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GUARANTEED JOB OPPORTUNITY ACT

JOINT HEARING

BEFORE THE

SUBCOMMITTEE ON EMPLOYMENT AND PRODUCTIVITY

AND

SUBCOMMITTEE ON THE HANDICAPPED

OF THE

COMMITTEE ON LABOR AND HUMAN RESOURCES UNITED STATES SENATE

ONE HUNDREDTH CONGRESS

FIRST SESSION

ON

S. 777

TO GUARANTEE A WORK OPPORTUNITY FOR ALL AMERICANS, AND FOR OTHER PURPOSES

APRIL 28, 1987

PART 2

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GUARANTEED JOB OPPORTUNITY ACT

TUESDAY, APRIL 28, 1987

U.S. Senate, Subcommittee on Employment and Productivity, and Subcommittee on the Handicapped, Committee on Labor and Human Resources,
Washington, DC.

The Joint Hearing convened, pursuant to notice, at 9:45 a.m., in Room SD-430, Dirksen Senate Office Building, Senator Paul Simon (Chairman, Subcommittee on Employment and Productivity) presiding.

Present: Senators Simon, Harkin, Weicker, and Cochran.

Senator **Simon**. The hearing will come to order.

I am sure my colleague, Senator Harkin, the Chairman of the Subcommittee on the Handicapped who should be chairing this meeting would not object to my calling the hearing to order very briefly. Let me hold off with any opening statements until after our first witness, Congressman Bill Coyne of Pennsylvania, because he has been waiting here for some time. He is one of the really fine Members of the House of Representatives.

If you can join us up here now, maybe we will hold off on opening statements. Would my colleague from Connecticut be willing to hold off any opening statements?

Senator **Weicker**. Mr. Chairman, I agree 100 percent. As a matter of fact, I am going to have my statement submitted for the record, as I do want to hear from all the witnesses. As you know, there is a Holocaust ceremony in the Capitol Rotunda and I think it is essential we get right down to hearing the witnesses.

Senator **Simon**. We will open this hearing in 60 seconds.

Senator **Weicker**. It is now official.

Senator **Harkin**. We have refrained from opening statements so we could get on with Congressman Bill Coyne's testimony. If it is okay, we will go ahead and hear him and then each of us can have——

Senator **Weicker**. I ask unanimous consent that mine be placed in the record.

Senator **Harkin**. Then I will ask unanimous consent that mine be placed in the record also. I will follow suit with my two leaders.

Senator **Simon**. I will ask that also.

Let me add one minute's worth of commentary. We are talking about unemployment. There is no group where the unemployment rates are more dramatic than among Americans with disabilities, and one of the most dramatic statistics I have seen recently is that among employable blacks with disabilities, the unemployment rate is 82 percent, and among the other 18 percent the average income is $4,000 a year in this good and great and rich country. We can do a lot better than that in America.

I will enter my full statement in the record. Thank you, Mr. Chairman.

Senator HARKIN. Thank you both very much, and our former colleague from the House, Congressman Coyne, from the 14th District of Pennsylvania. Welcome to the joint meeting of the two Subcommittees, Senator Simon of the Subcommittee on Employment and Productivity, and the Subcommittee I chair, on the Handicapped. You are welcome to the Subcommittee proceedings and we are honored to have you here.

STATEMENT OF HON. WILLIAM COYNE, A REPRESENTATIVE IN CONGRESS FROM THE 14th CONGRESSIONAL DISTRICT, STATE OF PENNSYLVANIA

Mr. COYNE. Thank you, Senator. I want to congratulate Senator Simon and Senator Harkin and Senator Weicker and the panel for addressing an issue that I think is very important, one of the most important issues that we face in the Congress of the United States and that is unemployment across the nation. It is heartening to think that there are Senators in the United States Senate who concern themselves with sufficiency of the employment opportunities of people in this nation.

I want to thank you for the opportunity to testify in support of the Guarantee Job Opportunities Program. I believe this bill fills an important gap in the current employment and job training equation in this country by establishing a program of public sector jobs for the hard-core unemployed.

While the existing Federal jobs training program has been successful in placing thousands of Americans in new jobs during the past several years, all of those jobs have been in the private sector. One problem with this approach is that it has tended to place a disproportionate emphasis on holding down the program's costs. One consequence of this policy has been that those jobless considered the most difficult to place in the private sector have often been neglected.

The focus has been, unfortunately, on finding jobs for those with extensive or specific jobs skills and those with high school or post-secondary education. Those lacking the right skills or a formal education all too often find themselves shunted to the end of the job line. In other words, those needing the least amount of training or the fewest number of support services have the highest probability of receiving assistance.

On the other hand, it strikes me that this approach to the problem of unemployment unfairly discriminates against those with the greatest need, the youth, minorities, and the disabled. Yet, despite the achievements of the current Federal program, there are still at least ten million Americans who want to work but cannot find a job. Where are these jobless supposed to turn for help?

I think one place is the program that this panel and Senator Simon and Senator Harkin have proposed. Your proposal is designed to compliment the current Federal job training program and address some of its deficiencies. I am especially pleased to note that discouraged workers are among the jobless that the guaranteed job opportunities program will assist in finding meaningful work in our economy.

This group of jobless all too often finds itself overlooked by the experts and by the statistics. They are the hidden unemployed, people who have a history of hard work, who want to work, but who have become so frustrated at the lack of opportunities that they are convinced that no jobs exist for them and as a result they have simply stopped looking for job opportunities.

In addition to discouraged workers, there is another group, the handicapped, that face formidable obstacles every day to obtaining gainful employment, even in strong economic times. These barriers to employment for the handicapped have been too slow in coming down.

There is simply no justification for denying employment, especially in the public sector, to any disabled American. A recent poll indicates that nearly half of America's disabled believe there is a lack of opportunity in the private sector for them. That is a distressing view, considering that this poll clearly demonstrates an overwhelming eagerness, willingness and desire of disabled Americans to work.

The private sector's record, by its own account, has not been strong on hiring the disabled. A survey of corporate managers revealed that 35 percent of the companies that they work for had not hired a disabled person in the past three years, and yet these same executives concede that it costs no more to employ a disabled person than one who is not.

Hopefully, your legislation can open some eyes as well as some doors for the disabled. It is encouraging to see the emphasis you place on education as an integral part of any job training and employment plan. A well-educated work force has been and will continue to be our most effective weapon in the highly competitive international marketplace. We clearly need a workforce that can adapt its skills to the demands of tomorrow's industries.

I can assure you that in my western Pennsylvania district of Pittsburgh, there would be no shortage of displaced and discouraged workers who would be eager to rejoin the workforce. The program outlined in your proposal offers them that chance and provides the added attraction of job counseling so that these workers can find permanent employment in the private sector.

These are not people who are looking for a handout from the government, nor do they expect something for nothing. I think they represent the majority of the unemployed that your bill targets for help.

Again, I want to congratulate Senator Simon on this bill that I think takes a giant step toward improving the prospects for millions of jobless who through no fault of their own see themselves shut out of existing job training employment opportunities.

I intend to vigorously support this important legislation in the House and I look forward to enactment by Congress and being signed into law by the President.

Thank you very much.

Senator HARKIN. Bill, thank you very much for a fine statement. Again, I am honored that you would take the time from your busy schedule to come over here and support this important piece of legislation.

I do not have any questions. Senator Simon?

Senator SIMON. No, I do not have any questions. I simply want to join in commending you for showing the sensitivity and the willingness to provide leadership on this. It becomes very easy, particularly with the way we finance political campaigns, to be paying attention to the wishes and whims of the powerful, rather than helping people who really need help in our society. You are one of those who are standing up to help people who really need help and I commend you.

Mr. COYNE. Thank you.

Senator HARKIN. Senator Weicker?

Senator WEICKER. I associate myself with the comments of my colleagues. It was a fine statement.

Senator HARKIN. Thank you very much, Bill.

[The opening statements of Senators Simon, Weicker, Harkin, and the prepared statement of Senator Stafford will now be inserted in the record at this point:]

OPENING STATEMENT OF SENATOR PAUL SIMON

Senator SIMON. The Subcommittee on Employment and Productivity has been conducting hearings on S. 777, the Guaranteed Job Opportunity bill I introduced to give an opportunity to all Americans who want to work an opportunity to be productive. Senator Harkin suggested that his Subcommittee on the Handicapped join us to look at the employment situation of Americans with disabilities. I am pleased that we are meeting together today.

We know that the figures are startling. Of some 27 million Americans of working age who are disabled, only about ⅓ are working. According to census data, the unemployment rate among black disabled Americans is around 84%. These figures show the overwhelming proportions of an unemployment problem we have simply ignored for too long. Because a large percentage of these individuals have lost all hope of ever being employed and are not actively seeking work, they represent a largely unseen part of our nation's unemployment picture. And they represent an uncounted share of the human potential of our country.

It is important for us to get these statistics on the record, to draw more attention to these realities and to begin to see just what these figures mean in terms of lives without hope and lost productivity. This hearing will put some of the information on the record and will give us an opportunity to look at specific recommendations for making inroads into the complex unemployment problem of persons with disabilities.

The picture is not without hope. When we have made an effort through legislation to get people with disabilities into productive work—through the Rehabilitation Act, for example—that effort has been enormously successful. There are no areas of federal involvement where we have seen more of an economic benefit to the nation, and the benefits in terms of human lives has been incalculable. We have many examples of ways in which the "abilities" of the disabled have enriched society. But when millions of our citizens with disabilities continue to live at home, with less income, less social life, and less hope than other Americans, it is clear that we have not done enough.

The richest resource our nation has is its human potential. We cannot afford to continue to lose this potential. For human, social and economic reasons, we must do more to move people from dependency to productivity. I know we will hear some helpful recommendations today on how we can do that, and I look forward to the testimony.

OPENING STATEMENT OF SENATOR LOWELL WEICKER, JR.

Senator WEICKER. Today the Subcommittee on Employment and Productivity and the Subcommittee on the Handicapped meet jointly to hear testimony on the status of employment for individuals with disabilities.

The interests of our two subcommittees overlap when it comes to issues related to the employment of persons with disabilities. The Rehabilitation Act, which is under the jurisdiction of the Subcommittee on the Handicapped, has been enormously successful in getting disabled people employed. Yet the unemployment statistics among the disabled indicate that the Rehabilitation Act programs are not enough. It is my hope that, by working together, these subcommittees will ensure that the needs of disabled Americans are recognized in any comprehensive employment legislation Congress considers.

Disabled individuals have demonstrated their capabilities. It is now up to us to continue to build upon their proven track record of success in becoming independent, productive taxpayers.

Last year, we made substantial strides forward in this regard through amendments to the Rehabilitation and Education of the Handicapped Acts. Last month, amendments were included in the Senate-passed Jobs for Employable Individuals Act to further enhance employment opportunities for the disabled. And this year, we will reauthorize the Developmental Disabilities Act, which contains an important employment priority for States.

But again, we are not doing enough. Today we will hear testimony on the status of employment from the perspective of disabled individuals themselves, and their employers. This testimony will be critical in helping both subcommittees understand what additional challenges remain for us to increase employment opportunities for all disabled individuals, regardless of the severity of their disability.

Finally, I would like to commend Senator Simon, chairman of the Subcommittee on Employment and Productivity, and Senator Harkin, chairman of the Subcommittee on the Handicapped, for holding this joint hearing, and I look forward to working with them and the other subcommittee members during this session of Congress to address the employment needs of disabled individuals.

OPENING STATEMENT OF SENATOR TOM HARKIN

Senator HARKIN, I want to take just a moment if I may to say how pleased I am that the Subcommittee on Employment and Productivity, under the chairmanship of Senator Simon, has chosen to focus on the unemployment of handicapped persons. It's refreshing to see the needs of disabled Americans addressed by the Senate outside of the traditional setting of the Subcommittee on the Handicapped. Thank you Mr. Chairman for agreeing to this joint hearing.

Although I am the new chairman of the Subcommittee on the Handicapped, it doesn't take a great deal of experience or insight to figure out that when we have two-thirds of all disabled Americans between the ages of 16 and 64 unemployed, and when two-thirds of that group want to work, but can't find or afford employment, we've got a real problem.

As a nation, we've progressed in our attitudes toward people with disabilities. We're beginning to view people with handicaps in terms of what they can do, not in terms of their limitations. However, we as a nation have a long way to go. Discrimination on the basis of handicap is still a major problem facing disabled people. Disabled people lack adequate training and education to enter the competitive employment market. They also face disincentives to employment. For some, in order for job opportunities to be meaningful, there must be accessible transportation, attendent care, and other necessary support services.

I have a brother, an older brother, who because he was deaf was told by his teachers at the school for the deaf he attended in Iowa that he would become a baker. Well he didn't want to become a baker. But he did for a short period. Fortunately, he eventually found other employment which he enjoyed. Thus, I guess, given the unemployment rate for handicapped persons, my brother was lucky to find any job at all. But, we as a nation cannot conclude that justice has been achieved when a handicapped person's opportunities and choices are limited. We must insist that handicapped persons have choices and that there are opportunities for advancement in a job. We must be talking about the same opportunities that nonhandicapped individuals take for granted—the dignity of working, of moving up in a job, of failing now and then, and of becoming part of our towns and communities.

In sum, we know that handicapped people are to be employed—we know that they want to be employed. We must ensure that handicapped people are provided the opportunities.

[The prepared statement of Senator Stafford follows:]

SENATOR ROBERT T. STAFFORD
OPENING STATEMENT
JOINT HEARING
APRIL 28, 1987

MR. CHAIRMAN, I CONGRATULATE YOU ON CONDUCTING A HEARING ON THE VERY IMPORTANT TOPIC OF THE EMPLOYMENT OF DISABLED INDIVIDUALS.

CURRENTLY THE PRIMARY PROGRAM AVAILABLE TO TRAIN INDIVIDUALS WITH DISABLILITIES IS THE FEDERAL VOCATIONAL REHABILITATION ACT. ACCORDING TO THE 1986 ANNUAL REPORT OF THE REHABILITATION SERVICES ADMINISTRATION 79 PER CENT OF THE 227,652 INDIVIDUALS REHABILITATED WERE PLACED IN COMPETITIVE JOBS. IN VERMONT AND IN OTHER STATES THE REHABILITATION AGENCIES HAVE BECOME VERY INNOVATIVE IN SERVING THE GREATEST NUMBER OF INDIVIDUALS WITH LIMITED RESOURCES. PART OF THIS SUCCESS HAS BEEN THE STRONG INVOLVEMENT OF BUSINESS.

GIVEN THE FACT THAT THERE ARE 14 MILLION DISABLED INDIVIDUALS OVER THE AGE OF 18 IN THIS COUNTRY AND ONLY FIVE MILLION OF THEM ARE EMPLOYED SPEAKS TO THE NEED THESE INDIVIDUALS HAVE IN BECOMING EMPLOYED. UNFORTUNATELY, THE INCOME LEVEL OF DISABLED INDIVIDUALS IS LOWER THAN FOR ANY OTHER MINORITY GROUP

IN THIS COUNTRY. OVER 50 PER CENT OF DISABLED AMERICANS HAVE A HOUSEHOLD INCOME OF $15,000 OR LESS. THIS IS MORE THAN TWICE THAT OF NON-DISABLED AMERICANS.

MR. CHAIRMAN, THE STATISTICS SPEAK FOR THEMSELVES OF THE LACK OF INCENTIVES TO ENCOURAGE THE EMPLOYMENT OF DISABLED INDIVIDUALS. I LOOK FORWARD TO HEARING FROM THE DISTINGUISHED WITNESSES WHO ARE WITH US TODAY.

Senator HARKIN. Our next panel would be Humphrey Taylor, President, Louis Harris and Associates, New York City, and Harold Russell, Chairman, President's Committee on Employment of the Handicapped.

Again, we welcome both of you to the panel. Harold, it is always good to see you again.

Mr. RUSSELL. It is always good to be here.

Senator HARKIN. I am afraid I am going to have to apologize and leave for a few minutes. We are having a markup in another committee just down the hall, and I have to go to the markup of Senator Metzenbaum's subcommittee and then I will be right back. I will be back in 20 or 25 minutes.

Senator SIMON. And let me just add, if anyone needs an interpreter here, there is an interpreter for the deaf. I guess we should be asking the question in sign language and not——

Senator HARKIN. Does anyone need an interpreter?

Senator SIMON. All right. Thank you.

Senator HARKIN. I am just told they are running late, so I do not have to leave right now. I can hear your fine testimony. Again, we certainly welcome you to the joint meeting of the two subcommittees.

I will just tell you that your statements will be made a part of the record in their entirety and you can proceed as you so desire, whichever one of you wants to go first.

Mr. Taylor?

STATEMENT OF HUMPHREY TAYLOR, LOUIS HARRIS & ASSOCIATES, INC., NEW YORK, NY; AND HAROLD RUSSELL, CHAIRMAN, PRESIDENT'S COMMITTEE ON EMPLOYMENT OF THE HANDICAPPED

Mr. TAYLOR. Mr. Chairman, Senators, it is a privilege to be here again if, for reasons which are beyond the understanding of a pollster, there has been a change in the chairmanship of the Committees since my testimony at the beginning of last year.

In that testimony, I summarized the key findings of the first ever survey of a cross-section of disabled Americans. I will not waste your time repeating what I said then, except to emphasize one point, the enormous human, social and economic benefits which would flow from increasing the number of disabled people in paid employment.

We found that there are some 27 million adult Americans living at home with physical, mental or psychological impairments, which, to put it in context, is larger than the number of adult black Americans and almost twice the number of adult Hispanics.

By almost any definition, these 27 million disabled Americans are uniquely underprivileged and disadvantaged. They are much poorer, much less well educated and, having much less social life, enjoy fewer amenities and have a lower level of life satisfaction than other Americans.

The big divide within the disabled population is between those who work and those who do not work. The data point overwhelmingly to the conclusion that the best way to improve the quality of life of most disabled Americans is to find them paid employment.

However, the sad truth is that only one in four of the 19 million disabled people age 16 to 64 are working full-time; a further 10 percent are working part-time, two-thirds are not working at all. And of this majority who are not working, fully two-thirds say they want to work. In other words, about 44 percent of all disabled adults under 65, that is almost 8.5 million people, want to work but cannot find a job.

The challenge which was posed by the first survey was, therefore, what can we do as a society to help find employment for more of these people.

An obvious question, of course, is could the private sector employ more of them, and, if so, what would it take to make this happen. I was delighted, therefore, when the Harris firm was asked by the International Center for the Disabled, the National Conference on the Handicapped, and the President's Commission on Employment of the Handicapped to conduct a new survey of private sector employers to try to answer these questions.

Let me add that this new survey was only made possible by generous grants from three Federal Government agencies, the Office of Human Development Services, the Employment and Training Administration, and the Social Security Administration, as well as support from the J.M. Foundation and the private sector.

This new survey, called ICD Survey II, Employing Disabled Americans, is based on 921 interviews with employers in large, medium size and smaller companies. At the risk of oversimplifying the findings, let me just check off a few which seem to be most relevant to this Committee:

1. Disabled people make very good employees. Overwhelming majorities of managers give disabled employees a good or excellent rating on their overall job performance. Disabled employees are highly rated by their employers on their overall job performance, on their willingness to work hard, on reliability, attendance and punctuality, productivity, and desire for promotion.

2. Cost is not a barrier to the increased employment of disabled people. A three-fourths majority of all three manager groups say that the average cost of employing a disabled person is about the same as the cost of employing a non-disabled person.

3. Well, that is obviously very good news, but it is only a small part of the total picture. Unfortunately, strong performance evaluations and an absence of cost barriers have not translated into widespread hiring of disabled employees. For example, only 43 percent of Equal Employment Opportunity officers in companies which have them say that their company has hired a disabled employee in the previous twelve months, a finding which helps to explain the low level of employment we reported in our first survey.

4. The biggest single barrier to the increased employment of disabled people is the shortage of qualified job applicants. Companies that have not hired disabled people in the past three years say that a lack of qualified applicants is the most important reason.

The message in this finding is very clear: Increase the pool of qualified disabled people through education and appropriate training efforts and the number who find work will rise dramatically.

5. A second key barrier is that few companies have established a policy or program for the hiring of disabled employees. Only 37

percent of managers say that their company has such a policy or program, and these are mostly large companies. These policies are important. Companies which have them are much more likely to hire disabled workers.

The survey also underlines the importance of the vital role of raising the consciousness of middle managers about employing disabled people and ensuring that hiring policies are followed, a role for top management.

6. Unfortunately, such leadership is rare. Managers generally display a low level of consciousness toward disabled people as a group. This is an important barrier to their increased employment.

7. On a more positive note, the majority of managers say that their companies can provide in-house training for disabled employees.

8. Other positive findings deal with the rehabilitation of disabled employees. Most employers who have dealt with employees who become disabled say that a majority of these employees return to work. Most employers are supportive of, and committed to, the rehabilitation of employees who become disabled. However, there is a fair amount of complacency. Most employers believe that the companies are already doing enough to rehabilitate disabled employees; only tiny minorities believe they should make any greater efforts.

9. That finding underlines a level of complacency and a lack of consciousness of the problems of disabled Americans generally. For example, most managers think that their companies are already doing enough to employ disabled people and should not make greater efforts to employ them.

10. We asked managers to rate the effectiveness of proposed changes, and we found that managers generally express strong support for many different proposed initiatives and policy changes designed to help increase employment of disabled people.

The proposals thought by employers to have the most potential were, in order of their perceived effectiveness: Establishing direct training and recruiting programs with schools and vocational rehabilitation agencies; having more companies provide internships or part-time jobs to disabled persons as an introduction to full-time jobs; having employers explain specific functional requirements as part of job descriptions for open positions; having the government provide additional tax deductions for expensive accommodations, or share in their cost; having the government subsidize salaries for severely disabled employees for a trial period; having disability professionals give technical assistance or counsel to employers for accommodations or problems with specific employees; and having chief executive officers establish voluntary employment targets for disabled people.

If I may very briefly summarize our findings, I would stress first of all the very important findings which are encouraging:

That employers give their disabled employees high marks as hard working, reliable and productive employees; that the cost of employing disabled people is not a significant barrier in most cases; and that most employers appear to be willing to consider the employment of more disabled people if they are qualified.

However, the evidence of this survey is that, without some new stimulation, the employment of disabled people is unlikely to increase significantly. Why?

Because most managers think their companies are already doing enough to employ disabled people and should not make greater efforts to do so; most employers believe that the shortage of disabled job applicants with appropriate qualifications is a major barrier to their employing more disabled people; and because employers give the hiring of disabled people a lower priority than the hiring of people from minority groups. And disabled people are less likely than are minorities or the elderly to be viewed as an excellent source of employees, because they lack experience or qualifications.

I conclude from the survey that efforts to increase the employment of disabled people will only succeed if there is an increase in the number of job applicants who are perceived by employers to be qualified, through better education and better training; and if employers are pressured, cajoled, incented, or lead to give the employment of disabled people a higher priority than they give it now.

If that happens, millions of disabled people will enjoy much richer and fuller lives than they do today. Thousands of employers will have more productive and reliable employees, and we will all benefit through the many economic benefits which come from moving people from welfare and dependency into productive employment. Thank you.

[The prepared statement of Mr. Taylor follows:]

LOUIS HARRIS AND ASSOCIATES, INC.

Statement of Humphrey Taylor
President, Louis Harris and Associates, Inc.
Senate Subcommittee on the Handicapped and
Senate Subcommittee on Employment and Productivity
April 28, 1987
Washington, D.C.

Mr. Chairman, it is a privilege to be here again even if, for reasons which are beyond the understanding of a pollster, there has been a change in the Chairmanship of your Committees since my testimony of January 1986.

In that testimony I summarized the key findings of the first ever survey of a cross-section of disabled Americans. I won't waste your time repeating what I said then -- except on one point -- the enormous human, social and economic benefits which would flow from increasing the number of disabled people in paid employment.

Among the most important findings of that survey were the following:

(1) There are some 27 million adult Americans living at home with physical, mental or psychological impairments, which is larger than the number of adult black Americans and almost twice the number of adult Hispanics.

(2) By almost any definition these 27 million disabled Americans are uniquely underprivileged and disadvantaged. They are much poorer, much less well educated and, have much less social life, enjoy few amenities and have a lower level of life satisfaction than other Americans.

(3) The big divide, within the disabled population, is between those who work and those who do not work. The data point overwhelmingly to the conclusion that the best way to improve the quality of life of most disabled Americans is to find them paid employment.

(4) However, the sad truth is that only one in four (25%) of the 19 million disabled people aged 16-64 are working full time; a further 10% are working part time; two-thirds are not working at all.

(5) Of this majority who are not working, fully two-thirds say they want to work. In other words, about 44% of all disabled adults under 65 -- that's almost 8½ million people -- want to work but can't find a job. In most cases they don't even try to find one.

The challenge which was posed by the first survey was therefore, "What can we do, as a society, to help find employment for these people?"

An obvious question, of course, is -- could the private sector employ more of them? And, if so, what would it take to make this happen? I was delighted, therefore, when the Harris firm was asked by the International Center for the Disabled, the National Council on the Handicapped, and the President's Commission on Employment of the Handicapped to conduct a new survey of private sector employers to find the answers to these questions.

Let me add that this new survey was only made possible by generous grants from three federal government agencies, the Office of Human Development Services, the Employment and Training Administration, the Social Security Administration, and by support from the J.M. Foundation and the private sector.

This new survey, The ICD Survey II: Employing Disabled Americans, is based on 921 interviews with employers in large, medium size and smaller companies. At the risk of over-simplifying the findings, let me check off what I see as the most relevant to your committees:

(1) Disabled people make very good employees. Overwhelming majorities of managers give disabled employees a good or excellent rating on their overall job performance. Only one in twenty managers say that disabled employees' job performance is only fair, and virtually no one says that they do poor work. Disabled employees are highly rated by their employers on their overall job performance, on willingness to work hard, on reliability, attendance and punctuality, productivity, and desire for promotion.

Nearly all disabled employees are thought to do their jobs as well or better than other employees in similar jobs.

(2) Cost is not a barrier to the increased employment of disabled people. A three-fourths majority of all three manager groups say that the average cost of employing a disabled person is about the same as the cost of employing a non-disabled person.

A Large majority of managers also say that making accommodations for disabled employees is not expensive. The cost of accommodations rarely drives the cost of employment above the average range of costs for all employees.

(3) Well, that's all very good news. But it's only a small part of the picture. Unfortunately. Strong performance evaluations and an absence of cost barriers have not translated into widespread hiring of disabled employees. For example, only 43% of EEO officers in companies which have them say that their company has hired a disabled employee in the past year -- a finding which helps to explain the low level of employment we reported in our first survey.

(4) The biggest single barrier to the increased employment of disabled people is the shortage of qualified job applicants. Companies that have not hired disabled people in the past three years say that a lack of qualified applicants is the most important reason.

The message in this finding is clear: increase the pool of qualified disabled people through education and appropriate training efforts and the number who find work will rise dramatically.

(5) A second key barrier is that few companies have established a policy or program for the hiring of disabled employees. Only 37% of managers say that their company has such a policy or program, and these are mostly large companies. These policies are important. Companies with them are much more likely to hire disabled workers.

Which underlines the fact revealed in other findings of our survey that top managers play a vital role in raising the consciousness of middle managers about employing disabled people, and ensuring that hiring policies are followed.

(6) Unfortunately, such leadership is rare. Managers generally display a low level of consciousness toward disabled people as a group. This is an important barrier to their increased employment. Clearly the consciousness of all managers -- top, middle, and line supervisors -- toward disabled people needs to be raised.

(7) On a more positive note, the majority of managers say that their companies can provide in-house training for disabled employees. Sixty percent of top managers and 61% of EEO officers say their companies can do this. Among small businesses, however, only 46% of managers say they can provide in-house training.

(8) Other positive findings deal with the rehabilitation of disabled employees. Most employers who have dealt with employees who become disabled say that a majority of these employees return to work. Most employers are supportive of, and committed to, the rehabilitation of employees, who become disabled. However, that does not mean that companies will do more in the future than they do now. Most employers believe that their companies are doing enough to rehabilitate disabled employees. Only tiny minorities believe they should make greater efforts.

(9) That finding indicates a level of complacency and a lack of consciousness of the problems of disabled Americans. For example, most managers think that their companies are already doing enough to employ disabled people, and should not make greater efforts to employ them. Sixty-seven percent of top managers, 71% of EEO officers, and 70% of department heads and line managers think that their companies are doing enough now to employ disabled people.

However, in a somewhat contradictory response, majorities of managers also think it is somewhat likely or very likely that their companies will make greater efforts to employ disabled people in the next three years. But even if many managers are really willing -- at least in theory -- to try harder to employ disabled people, they will only do so if there are more qualified applicants.

(10) We asked managers to rate the effectiveness of proposed changes, and we found that managers generally express strong support for many different proposed initiatives and policy changes designed to help increase employment of disabled people. These include steps and changes that could be taken by employers, federal and state agencies, legislatures, private rehabilitation agencies and placement services, and foundations.

The proposals thought by employers to have the most potential were, in order of their perceived effectiveness:

-- Establishing direct training and recruiting programs with schools and vocational rehabilitation agencies.

-- Having more companies provide internships or part time jobs to disabled persons as an introduction to full time jobs.

-- Having employers explain specific functional requirements as part of job descriptions for open positions.

-- Having the government provide additional tax deductions for expensive accommodations, or share in their cost.

-- Having the government subsidize salaries for severely disabled employees for a trial period.

-- Having disability professionals give technical assistance or counsel to employers for accommodations or problems with specific employees. And

-- Having chief executive officers establish voluntary employment targets for disabled people.

IN CONCLUSION

There are several important findings in this survey which are very encouraging:

-- Employers give their disabled employees high marks as hard working, reliable and productive employees.

-- The cost of employing disabled people is not a significant barrier.

-- Most employers appear to be willing to consider the employment of more disabled people if they are qualified.

However, the evidence of this survey is that, without some new stimulation, the employment of disabled people is unlikely to increase significantly:

-- Most managers think their companies are already doing enough to employ disabled people and should not make greater efforts to do so.

-- Most employers believe that the shortage of disabled job applicants with appropriate qualifications is a major barrier to their employing more disabled people.

-- Employers give the hiring of disabled people a lower priority than the hiring of people from minority groups. And disabled people are less likely than are minorities or the elderly to be viewed as an excellent source of employees -- because they lack experience or qualifications.

I conclude from the survey that efforts to increase the employment of disabled people will only succeed therefore if:

- There is an increase in the number of job applicants who are perceived by employers to be qualified -- through better education or training.
- And if employers are pressured, cajoled, incented, or lead to give the employment of disabled people a higher priority than they give it now.

If that happens millions of disabled people will enjoy much richer and fuller lives than they do today. Thousands of employers will have more productive and reliable employees. And we will all benefit through the many economic benefits which come from moving people from welfare and dependency into productive employment.

Senator HARKIN. Humphrey, thank you very much for your fine statement.

Harold, let us go to you and then we will have questions.

Mr. RUSSELL. Thank you, Senator.

I am very pleased to be with you this morning, having been given this opportunity to comment on this most important legislation, the Guaranteed Job Opportunity Act. I am very pleased that the language of this Act includes some provisions for people with disabilities.

Without specific inclusion of people with disabilities, we know from sad experience that the chances are that they will be excluded from participation in many of the programs that this Act would establish. They would be excluded because they have been perceived as taking scarce resources away from others. They would be excluded because this is the history of people with disabilities—separate, segregated and excluded.

"Not working is today's definition, the truest definition of what it means to be disabled in the United States. This definition comes from the 1986 Lou Harris and Associates study, "Disabled Americans 'Self-Perceptions." The study reinforces our knowledge of disability, and underlines our need for action.

Over two-thirds of working age Americans with disabilities are out of the labor force. This is the highest unemployment rate of any minority group, higher even than the rate of unemployment found among inner-city black teenagers. To be disabled in the United States is to be less educated, to have fewer skills, to have lower incomes, to have no job. Yet, among two-thirds of the disabled Americans who are out of the labor force, 66 percent would like to have a job. Motivation is clearly there.

And this Act would be instrumental in seeing that these motivated people get the training and the job opportunities that they so badly need and want. Thirty-eight percent of working-age people with disabilities are either not working or are working only part-time, and say their under-education and lack of marketable job skills are important reasons why they are not working full-time.

This and other information of the Harris Survey are included and analyzed in a new publication, "Out of the Job Market: A National Crisis," just released by the President's Committee.

Mr. Chairman, I have a copy to leave with you today and I have also copies to be mailed to all the members of the Committee. Additional copies are being sent to all of those who are interested.

Last year, the President's Committee on Employment of the Handicapped joined the National Council on the Handicapped and the International Center for the Disabled in sponsoring a second Louis Harris Survey. This study, entitled "Employing Disabled Americans," surveyed employers, their attitudes and practices.

"Employing Disabled Americans" finds enormous acceptance among employers toward workers with disabilities. Overwhelming majorities of managers rate employees with disabilities as good or excellent on overall job performance. This strong performance rating does not translate into jobs, unfortunately.

Only 43 percent of EEO officers say that their companies hired disabled employees in the past year; 66 percent of managers cite the lack of qualified applicants as the most important reason that they have not hired any people with disabilities within the past three years.

"Employing Disabled Americans" once again identifies the lack of job skills and low education levels found among many Americans with disabilities. It heightens our concern for job training and retraining, for many adults with disabilities received their education prior to 1975, long before the Education for All Handicapped Children Act became the law of the land.

The President's Committee recently issued two studies concerning data pertinent to the subject of these hearings. The first summarized the participation of people with disabilities in the Job Training Partnership Act, JTPA. Results continue to improve with participation of adults and youth with disabilities in Title IIA, increasing from 7.6% in PY 1984 to 9.7% in PY 1986. In PY 1984, 7.5% of all Title II-A. youth terminees were youth with disabilities. In PY 86, that figure rose to 11.6%.

Although some progress is very evident, there are problems. Participation rates vary significantly among State to State. PY 1986 participation of youth with disabilities ranges from a low of 1.4% to a high of 49.1%.

The second study is the report of first-year college students with disabilities, prepared in cooperation with the American Council on Education. Recognizing the importance of higher education in preparing individuals for a career, we need to know how well students with disabilities are faring.

The most recent data indicates that 7.4 percent of the 1985 college freshmen had a disability, a significant improvement over the 2.6 percent of college freshmen with disabilities in 1978, which was the first year of recorded data.

Recent congressional actions will serve to insure continued progress. The 1986 amendments to the Rehabilitation Act certainly strengthened that program. The provisions in the Jobs for Employment Dependent Individuals will be helpful, yet much more needs to be done.

By specifically including people with disabilities in the Guaranteed Job Opportunity Act, Congress will have taken a major step to increase job opportunities for people with disabilities, a step that must be taken to begin to redress that special, segregated, excluded status that haunts Americans with disabilities.

Thank you, Mr. Chairman. I appreciate this opportunity to appear before this distinguished Committee.

[The prepared statement of Mr. Russell with attachments follows:]

Supplemental Testimony

of

Harold J. Russell

Chairman

President's Committee on Employment of the Handicapped

for

the United States Senate

Subcommittee on Employment and Productivity

and

Subcommittee on the Handicapped

on

Employment of Persons with Disabilities

As I mentioned in my testimony on April 28, 1987, the President's Committee recently published "Out of the Job Market: A National Crisis." The following excerpts from this publication, which is available free upon request, present clearly the intolerable employment crisis facing the disability community today. They indicate furthermore, the strong desire of people with disabilities to be employed and to be integrated, productive members of our society.

"Today, as the economy enters its fourth full year of recovery from the 1981-83 recession, unemployment in our nation is in the 7% range. Some 11 million jobs have been created in the past 48 months alone. Participation by women in the nation's labor force has never been higher.

"Yet there is a segment of the population that has regressed proportionally in its participation in the labor force. Disabled people today are less likely to be at work than they were in 1980-and even less than in 1970.

"Just one-third of disabled working-age Americans work. Among disabled women, just one in every five has a job. Among disabled men, about four of every ten have jobs.

"The cost to our nation of tens of millions of disabled persons out of the labor force is staggering. In 1985, the Federal Government spent $62 billion on subsidies, medical care, and other programs for disabled persons, of which more than 93% was to support out-of-work individuals with disabilities.

"There is a popular myth that disabled people prefer to receive benefits rather than work. In this publication, we explode that myth. Sixty-six percent of all disabled adults of working age (16-64 years old) who do not now work say they want to work. While 70% of disabled beneficiaries say they would lose benefits if they worked full-time, just 18% of those asked in a nationwide poll by Louis Harris and Associates to identify important reasons why they were not working cited loss of benefits as a major concern. Five million disabled Americans are on Social Security Disability Insurance or Supplemental Security Income rolls---but many would rather leave those rolls and go to work."

A number of employers, both large and small, have developed some outstanding initiatives to help rectify this problem. Although they certainly are not sufficient to reverse the situation, I would be remiss if I did not mention some of these efforts.

There are two main types of private sector initiatives: (I) those where businesses form an alliance in order to achieve specific goals; and (II) those whereby individual companies excel at recruitment or retention of workers with disabilities.

Type I is best typified by BIPED (Business Information Processing Education for the Disabled), a non-profit corporation to train individuals with severe physical disabilities in computer programming. Formed in 1980 and located in the Fairfield, CT/ Westchester County, NY area, BIPED has provided tuition-free education in computer programming and related data processing areas to persons with disabilities, with the concurrent objective of placing graduating students from the BIPED program in viable jobs. Some of the companies involved from its inception are Perkin-Elmer Corp, GTE, IBM, GECC, American Can Co., Aetna Life & Casualty, Xerox, Readers Digest and Tombrock Corp.

Another outstanding example of a group movement is the Massachusetts Corporate Partnership Program. This unincorporated alliance of more than a hundred companies exchanges information on job opportunities and accommodations for people with disabilities, as well as updated resources on job-ready clients and agency services. The founders of the Partnership were the major firms around Boston, but the Partnership now includes many smaller businesses throughout Massachusetts.

NEABIR, The New England Association of Business, Industry and Rehabilitation, Inc., is a regional network of Projects With Industry programs with sites throughout New England. Although grant money is provided through State Vocational Rehabilitation Services, companies are heavily involved in developing relevant training programs and hiring trained persons with disabilities. Companies involved over the years have been Pratt & Whitney Aircraft Division of United Technologies, Aetna Life and Casualty, Northeast Utilities, Friendly Ice Cream Corp., General Dynamics, CIGNA Corp., Dow Chemical U.S.A., The Travelers, Sears, Roebuck & Co., Raytheon, and many many local businesses.

Other companies are grouped around a trade or industry. The National Restaurant Association is responsible for the involvement of hundreds of restaurants in training and hiring people with disabilities by actively bringing business and rehabilitation together in consortia. Companies within these trade groupings, such as McDonald's, Marriott Corporation etc. have been very active.

In Iowa, in FY 1984-85, 185 job placements in the food service industry alone were achieved. Too numerous to mention here in its entirety, the list includes Pizza Hut, Denny's, McDonald's, Ramada Inn, Holiday Inn, Hardee's, SAGA, Hilton Hotels, Stouffers, Wendy's, as well as many local small companies. Outstanding for their strong training programs are McDonald's (the McJobs Program), Burger King (B-Kapable), Marriott and Sheraton. Other trade groupings through which many training and hiring projects have been achieved are the Edison Electric Institute (the public service power companies) and the Electronics Industry Foundation.

Type II consists of the many individual exemplary employer programs. Each year the President's Committee and the State Governors' Committees recognize both large and small empoyers for their outstanding commitment and contributions.

Examples: ITT, both in the USA and abroad, has hired and established special training courses for people with visual and hearing impairments.

DuPont, for many years the leader in the field of hiring people with disabilities, has excelled in retaining persons with limitations, as have 3M Corporation, AT&T, Sears, Roebuck and Co, and other "giants" of business.

Control Data has put its own technology to good use for itself and its employees with disabilities, and developed a program called "Homework" for home-based employees with severe disabilities.

The 3M Corporation is a pioneer in providing special aids and services as well as in-house rehabilitation to employees with disabilities.

Merck & Co., like Dupont, focuses on skills and knowledge rather than handicaps in order to retain extremely valuable workers with disabilities.

A smaller company, Herman Miller, has a special transitional work program for persons disabled on the job to enable them to gradually return to fulltime employment.

An even smaller business, Sea World of Calfornia, working with the Association of Retarded Citizens, not only utilizes many men and women with developmental disabilities in their operation, but also teaches Association clients good work habits so they can be competitively employed at other companies.

In spite of the excellent intentions and successes of these and other unmentioned programs, the employment status of most Americans with disabilities is grave, and intolerable. Much, much more needs to be done by all sectors of our society. The time is long past for this Nation to waste the vast human resources and potential of all of our citizens, whether they happen to have a disability or not.

The President's Committee on Employment of the Handicapped

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June 5, 1987

The Honorable Tom Harkin
Chairman, Subcommittee on the Handicapped
Committee on Labor and Human Resources
U. S. Senate
Washington, DC 20510

Dear Senator Harkin:

It is a pleasure to write and thank you for the opportunity to testify on employment of individuals with disabilities before the Subcommittees on the Handicapped and on Employment and Productivity.

I have reviewed and edited the transcript of my testimony and, as requested, am returning it to Mr. Powell. I am sending him, also, an additional statement which I hope can be included in the record. It contains several excerpts from the President's Committee's recent publication "Out of the Job Market: A National Crisis", which clearly summarize the unemployment crisis in the disability population and also the eagerness of individuals with disabilities for employment.

Although the unemployment rate among individuals with disabilities is intolerably high, it would be unfair not to note that outstanding efforts are being made by some employers to recruit, train, place, retain and advance workers with disabilities. In the hope that as more employers learn what can be done, more will be done, I am also including information on a number of their initiatives.

Dignity, Equality, Independence through Employment

Associate Members

The Secretary of State
The Secretary of the Treasury
The Secretary of Defense
The Attorney General
The Secretary of the Interior

The Director of the United States Information Agency
The Secretary of Agriculture
The Secretary of Commerce
The Secretary of Labor

The Secretary of Education
The Secretary of Health and Human Services
The Secretary of Housing and Urban Development
The Secretary of Transportation

The Administrator of the Veterans Administration
The Director of the Office of Personnel Management
The Administrator of the General Services Administration
The Postmaster General

Once again, I must thank you and say how eager I am to continue to work with you to improve opportunities for the independence for our citizens with disabilities.

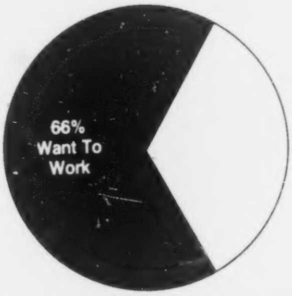
Sincerely,

Harold Russell

Harold Russell
Chairman

Out of the Job Market:

A National Crisis



Two-thirds of disabled adults without jobs say they want to work — including homemakers and persons over 65 years of age.

**The President's Committee
on Employment
of the Handicapped
Washington, D.C. 20036**

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Executive Summary by Harold Russell

Today, as the economy enters its fourth full year of recovery from the 1981-1983 recession, unemployment in our nation is in the 7% range. Some 11 million jobs have been created in the past 48 months alone. Participation by women in the nation's labor force has never been higher.

Yet there is a segment of the population that has regressed proportionally in its participation in the labor force. Disabled people today are less likely to be at work than they were in 1980 — and even less than in 1970.

Just one-third of disabled working-age Americans work. Among disabled women, just one in every five has a job. Among disabled men, about four of every ten have jobs.

The cost to our nation of tens of millions of disabled persons out of the labor force is staggering. In 1985, the Federal Government spent $62 billion on subsidies, medical care, and other programs for disabled persons, of which more than 93% was to support out-of-work individuals with disabilities.

Ironically, American businesses have invented remarkable new technologies that actually do the things many disabled people can't do on their own. We have machines that "read" typed materials automatically. We have inexpensive devices that "speak" text, so learning-disabled or blind persons can hear what they cannot read. We have machines that "hear" and "understand" speech — so that people who are very severely disabled and cannot move their fingers can, and do, work. Just around the corner are voice recognition technologies that will let deaf and severely hearing imparied people understand conversational speech, including television, radio, and the telephone.

Most of these aids are here, now. But few employers know about them — and fewer disabled people are aware of how dramatically these devices could change their lives. There are other problems as well. Costs of the new aids often are high. And, each advance in technology helps nondisabled people at least as much as it does persons with disabilities. Here, as in so many other areas of employment for people with disablities, we find a daunting communication gap. A gap that must be filled.

The challenge is clear.

Equally clear is the role the President's Committee and Governor's Committees on Employment of the Handicapped must play. As the Federal Government's only organization focusing exclusively upon employment of persons who are disabled, the President's Committee can stimulate private sector initiatives among its thousands of volunteers and many corporate members. The President's Committee can provide, through its Job Accommodation Network, toll-free help to employers looking for accommodations for disabled jobseekers and workers. Through Disabled USA and other publications, the President's Committee can communicate directly to tens of thousands of disabled adults and tell them about new employment opportunities. Through conferences that bring together employers, disabled people, parents, and advocates, the President's Committee can provide a forum for solutions to long-term problems that have to date denied disabled people a chance to support themselves and their families, perhaps the most basic building block of The American Dream.

The President's Committee understands the challenge before all of us — and is determined to respond. The Committee recently reorganized its staff to channel it's energies directly toward the real issue — doing everything possible to enhance employment of persons with disabilities. The Committee's Annual Meeting has been revamped and charged with the task of assessing progress toward the goal of providing every disabled American who wants to work with a real chance at a job. The Committee is reaching out to organizations representing women, disabled veterans, members of minority groups, and older Americans to link its arms with theirs, so that together we can solve the urgent employment problems of all people who have disabilities.

In this report, we offer exciting information suggesting that, after decades of difficulty in placing disabled people in suitable jobs, both employers and disabled adults themselves now are poised to make a new beginning. We have a better chance of success now than at any time in the 39 years the President's Committee has been in existence.

There is a popular myth that disabled people prefer to receive benefits rather than work. In this publication, we explode that myth. Sixty-six percent of all disabled adults of working age (16-64 years old) who do not now work say thay want to work. While 70% of disabled beneficiaries say they would lose benefits if they worked full-time, just 18% of those asked in a nationwide poll by Louis Harris and Associates to identify important reasons why they were not working cited loss of benefits as a major concern. Five million disabled Americans are on Social Security Disability Insurance or Supplemental Security Income rolls — but many would rather leave those rolls and go to work.

Three other trends are converging to open for us a window of opportunity: the changing nature of jobs in America, the aging of the baby-boom generation, and the emergence of new technologies. By taking advantage of these factors, we as a nation can place hundreds of thousands of disabled Americans into good jobs — and sharply reduce Federal disability benefit spending.

Harold Russell

Employers and disabled adults themselves now are poised to make a new beginning.

For most of the world's history, people with disabilities have been hidden away in attics, institutions, and "special programs". The first real employment breakthrough for large numbers of persons with disabilities came during World War II, when hundreds of thousands were put to work while "our boys" were overseas. By all accounts, the disabled employees performed very well.

In 1945, millions of American military men returned from active service. While many took advantage of the "GI Bill" to go to college, large numbers resumed the jobs they had held prior to Pearl Harbor. In doing so, they displaced many women and individuals with disabilities who had been working to maintain domestic production.

America's priority in those post-war years was to return the jobs to veterans, not to reward people with disabilities who had performed civilian work at home. This is the way most people felt it should be. In retrospect, perhaps more should have been done to capitalize on the performance record of people with disabilities.

As it was, in August 1945, Congress passed a joint resolution calling for a "National Employ the Physically Handicapped Week". The purpose was to encourage employers to use the skills that workers with disabilities had developed during the war years. Two years later, an Executive Order formally established the "President's Committee on National Employ the Physically Handicapped Week".

Consumer Involvement and Volunteer Action

From the beginning, people with disabilities were key players in the President's Committee. In fact, it was Paul A. Strachan, president of the American Federation of the Physically Handicapped, himself a deaf individual with other disabilities as well, who spearheaded the effort to create the Committee.

The President's Committee always has been organized primarily around volunteer action. Congress appropriated few funds to carry out nationwide activities. In addition, for years there were no laws or "affirmative action" guidelines for employers. The term "reasonable accommodation" was not even coined until the Committee was already in its second decade. Since there were no laws, there were no enforcement mechanisms for action against employers who did not hire disabled people until the 1970's. There were — and are — no quotas, goals or timetables for measurement of progress. Still, even in its first year, the Committee's work resulted in considerable progress in generating jobs for persons with disabilities — progress that has continued.

"It's Good Business"

A 1948 study by the Bureau of Labor Statistics of the U.S. Department of Labor provided Information about job performance by people with disabilities that the President's Committee was to use over the years in communicating with the nation's employers. The Bureau of Labor Statistics survey found that, on the average, workers with disabilities had fewer accidents, were absent no more often, and most important, were as productive, and at times more productive, than workers without disabilities. These facts, eye-opening at the time, have since become common knowledge among employers, in large part because of the Committee's work.

It was not until 1973 that Congress put any teeth into Federal programs on employment of disabled individuals. In Public Law 93-112, the Rehabilitation Act, Congress said in Section 503 that firms doing business with the Federal Government must take planned "affirmative action" in employing, advancing, and supervising people with disabilities. One year later, in the

Vietnam-era Veterans Readjustment Assistance Act of 1974, Congress used virtually the same language to require, in Section 402, that contractors and sub-contractors take affirmative action in hiring Vietnam veterans and disabled veterans.

In a country of about four million employers, Congress restricted Federal requirements to take affirmative action toward handicapped individuals and disabled veterans to "federal contractors". This limited affirmative action to 225,000 establishments in 30,000 companies handling contracts with Federal agencies and in their 75,000 sub-contractors. Thus, only some employers are affected by Sections 503 and 402.

Federal Regulations

Authority to implement and enforce these provisions was given to the U.S. Department of Labor's Office of Federal Contract Compliance Programs (OFCCP). The President's Committee Affirmative Action Committee members participated on task forces writing the regulations. Once they were published, the President's Committee assumed the role of communicating the provisions of the statutes to employers and to people with disabilities alike — distributing 100,000 copies of a pocket guide on Section 503, providing technical assistance to employers and people with disabilities, and hosting many conferences on the regulations.

Neither Section 503 nor Section 402 requires any goals or timetables. There are no numbers to report or to follow. Rather, the regulations implementing these statutes say that each handicapped individual or disabled veteran who qualifies for a particular position must be given an equal opportunity to get that job. "Reasonable accommodations" are to be made by the contractor or subcontractor to the known limitations of the individual. Company facilities used by all employees, such as employment offices, company cafeterias, and restrooms are to be made physically accessible. Posters proclaiming the company to be an affirmative action employer of persons with disabilities are to be prominently displayed in the workplace.

People Talking to People

The President's Committee hosted meetings at which company executives talked with consumer advocates about how compliance could be improved. In the mid-1970's, the committee issued the first widely disseminated summary of disablity demographics. One in Eleven responded to employer inquiries asking, "How many handicapped people are there?" At the Annual Meeting of the President's Committee, seminars were held at which experts explained how the statutes worked. Employers told other employers what lessons they had learned in interpreting regulatory terms such as "handicapped individual", "reasonable accommodation", and "affirmative action".

The Annual Meeting routinely attracted about 4,000 people to the nation's capital. In addition to scheduled speakers and workshops, these meetings provided a forum for advocates, employers, educators, and service providers. Sometimes, these ad hoc sessions produced unexpected results. It was during the 1974 Annual Meeting, for example, that disability advocates met to form the American Coalition of Citizens with Disabilities (ACCD), a group that became the premier advocate for people with disabilities during the late 1970's and early 1980's.

When regulations implementing Section 504 of the 1973 Rehabilition Act appeared in 1977, the President's Committee brought together representatives from the U.S. Department of Health, Education and Welfare (HEW since split into the Department of Health and Human Services and the Department of Education), on the one hand, and the Department of Labor, on the other. The Committee invited advocates for disabled people and experts on rehabilitiation to these sessions. In these meetings, we sought to find solutions to problems facing employers who were subject to the somewhat different requirements of Sections 503 and 504.

Publications

The President's Committee also cooperated with the Public Affairs Committee, a private organization in New York City, to produce two very widely disseminated pamphlets on employment of disabled people. We used Performance magazine (later Disabled USA) to spread the word about employment of people with disabilities. And we issued reports to respond to employer desires to learn more about the affirmative action implications of specific disabling conditions, such as lower back pain, alcoholism and drug abuse, and mental retardation.

Over the years, however, we at the President's Committee came to appreciate keenly that changing the attitudes of employers toward people with disabilities may take as long as a generation. Laws can change behavior, but not necessarily attitudes.

Focus on Employment

During the 1970's and early 1980's, the President's Committee was the only national organization which addressed issues relating to disability. Today, there are groups, agencies and programs which deal with such concerns as independent living and transporation. Thus the President's Committee can use its full energies to focus upon employment.

This concentration on employment is reflected, for example, in the 30 local conferences on "Pathways to Employment" that the President's Committee has sponsored, and our successful efforts to help people with disabilities to become eligible for participation in Job Training Partnership Act (JTPA) programs. It appears, too, in our cooperation with the Dole Foundation to publish Disabled Americans at Work and our series of four booklets on demographics: Disabled Adults In America, Disabled Women in America, Black Adults with Disabilities, and Disabled Adults of Hispanic Origin. Each focuses exclusively upon working-age disabled individuals.

It is reflected, as well, in our new format for the Annual Meeting. The 1986 meeting, for example, became "The National Conference on Employment of People with Disabilities." And it is reflected in the way we have revitalized our organizational structure to take increased advantage of our staff's expertise.

Substance Abuse

In recent years, some new aspects of employment of people with disabilities have surfaced. One that particularly troubled many employers was the decision by Congress and the courts that people who are alcoholics and drug abusers are in fact handicapped individuals under certain circumstances. The Federal government itself, under the Alcohol Abuse Act of 1970, for example, must provide medical treatment and rehabilitation services to Federal employees who have alcohol or drug problems. Only if such services are not successful may an agency proceed to dismiss the employee. Under terms of Public Law 95-602, the 1978 Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments, individuals with substance abuse problems that do not result in work-related problems may not be discriminated against, and must be accorded counseling and other assistance by the employer. The President's Committee responded by offering assistance to employers concerned with the problem.

JAN

One of the most significant undertakings by the President's Committee in recent years has been formation of JAN — the Job Accommodation Network. Created by the Employer Committee of the President's Committee, JAN is funded by grants from the National Institute on Disability and Rehabilitation Research and The Services Administration. The President's Committee administers the program and the toll-free lines (1-800-JAN-PCEH) are staffed at the Research and Training Center at the University of West Virginia.

JAN provides employers with an opportunity to talk with other employers about reasonable accommodations. A computerized database containing more than 5,000 accommodations which have actually been made by employers is searched by trained human factors consultants in response to specific requests by employers. Publicized in the *Wall Street Journal*, *Harvard Business Review*, and other highly respected publications reaching business people, JAN is growing each month. Since its founding, JAN has received more than 4,000 calls for information and assistance. Ninety-four percent of those calling have said that JAN met their needs — and 100% reported that they would use JAN again the next time they had an accommodation need.

New Challenges

Even as we are meeting these challenges, new ones surface. In late 1985 and early 1986, disability employment experts concluded that individuals with acquired immune deficiency syndrome (AIDS) are, in fact, handicapped individuals. This finding startled many employers, who are wondering what to do for their employees who contract AIDS. As more than 26,000 instances of AIDS have been reported, the problem is spreading. While BankAmerica and some other West Coast firms have developed guidelines for dealing with AIDS, surveys show, most other companies have not developed clear-cut policies regarding instances of AIDS in the workplace. A small percentage have formal, written policies. The President's Committee addressed the issue in a special seminar at the 1986 Annual Meeting, and has issued a policy developed by its Employer Committee and its Medical Advisory Committee.

As we review the past in preparation for our 40th anniversary in 1987, the President's Committee recognizes the need to keep looking ahead. In this publication, we focus on current and emerging issues in disability employment — and on directions for future action.

In late 1985 and early 1986, disability employment experts concluded that individuals with acquired immune deficiency syndrome (AIDS) are, in fact, handicapped.

What is happening in the American labor force — is it prepared to accept more jobseekers with disabilities? If so, what kinds of jobs would these people do?

Working

In America today, about 118,000,000 people between the ages of 16 and 64 work full or part-time. They represent about 47% of all Americans — but 78% of the 151,000,000 persons in that age range. Most Americans between the ages of 16 and 64, that is, work.

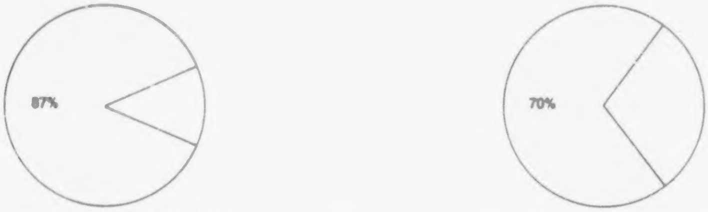
The proportion of working-age men who work is 88%. And that of working-age women who work is 69%. In fact, even among mothers with school-age children, a majority work.

We see a very different picture when we look at people who are disabled.

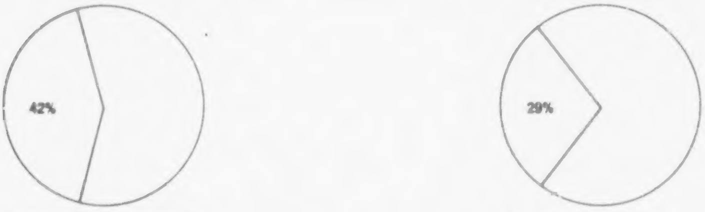
Of America's working-age individuals with disabilities, just 4,366,000 worked full or part-time in 1984. That is 12% of all disabled Americans — and 35% of the 13,000,000 disabled persons of working age. Most disabled people between the ages of 16 and 64, then, don't work. The stunning fact is that two-thirds don't have jobs. The proporation of working-age men with disabilities who worked at all in 1984 is 42%. And that of working-age women with disabilities who worked full or part-time, year-round or part-year, is just 29%. Many had part-time or part-year jobs. In fact, only three in every ten disabled working-age males and just two in every ten working-age females with disabilities had full-time jobs.

These numbers are the most recent we have. They come from the highly respected "Current Population Survey" of the U.S. Census Bureau. The study was done in March, 1985.

Chart 1: WORKING OR NOT WORKING



Males: Nondisabled Working **Females: Nondisabled Working**



Males: Disabled Working **Females: Disabled Working**

Most Americans work full-time or part-time. By contrast, most disabled adults do not.
Source: U.S. Bureau of Census, 1985.

The Labor Market

America's jobs are changing very dramatically. Five decades ago, 12,500,000 people worked on farms; today, just 3,750,000 do. Ten years ago, 1,139,000 workers were engaged in making steel and other metal products; today, 300,000 fewer are. By contrast, in 1970, 14,770,000 Americans were managers or professionals; by 1980, 22,653,000 were, for a 50% increase in just one decade. Among personnel managers, the growth over those ten years was a staggering 340%, from 65,000 to 220,000; among architects and urban planners, it was 100%; and among executives and other managers, it was 75%.

Twenty years ago, much construction was of factories, warehouses, and assembly plants. There were understandable obstacles facing people with disabilities looking for work in such buildings — most jobs involved heavy lifting, fine-motor control activities, and a lot of moving around. And there was danger for people who were deaf, who were blind, or who had epilepsy, because cranes and other heavy equipment could cause them to be injured on the job.

Today, however, 70% of all U.S. jobs are service jobs — and half are information positions. Most buildings going up now are not factories but office facilities. We have slashed agricultural employment to single-digit levels (about 3% of all employees work on farms). And we have exported to other countries many hundreds of thousands of manufacturing jobs.

The fastest-growing jobs in today's market are in sales and telemarketing, health care, financial services, leisure and travel services, and information collection and interpretation. These jobs involve much less risk of accident or injury to workers. In additon, of course, regulation of workplace safety is greatly improved over what we have known in the past.

If there ever were legitimate life-safety reasons for not employing people who have disabilities those reasons are all but gone today.

Technology

One of the most fascinating changes of the 1980's with respect to the prospects for gainful employment by persons with disabilities is the emergence of high technology equipment and software that literally does what some disabilities prevent.

Many thousands of people who are blind have been told, over the years, that they cannot be employed "because you can't keep up with the paperwork". Today, we have the following aids readily available:

- **Scanners,** that "read" reports, letters and other documents as rapidly as eight pages per minute and automatically enter text into a word processor or microcomputer. That is faster than most sighted people can read — and far faster than any clerk/typist can type.
- **Speech synthesizers,** that "speak" out loud whatever words are on the screens of work processors or microcomputers. Many blind people listen to these synthesizers at a speed of 350 words per minute, or twice as fast as most people talk.
- **Braille printers** that work with word processors or microcomputers to automatically translate into Braille virtually any textual information.

Individuals who are blind not only can "keep up with the paperwork", but actually can do so as fast as most sighted people. Significant problems remain: costs are often high, speech synthesizers won't work with some software programs, and the trend toward more graphics and "Icons" on computer screens creates difficulties for many individual who are blind.

For people who are deaf, the age-old excuse for not being hired is "You can't use the telephone". Today, hundreds of thousands of deaf people have Telecommunications Devices for the Deaf (TDDs) that allow them to talk with anyone else who also has a TDD — or, through a "TDD relay service", with anyone anywhere who has a telephone. In 1985, one company introduced a software program that automatically converts messages composed on the keys of any touch-tone telephone into printed words that appear on the screen of a microcomputer.

For people who cannot type conventionally, we have inexpensive aids that permit them to "type" by pointing a light pen at the letters they want entered. We have other devices that expand one or a few typed letters into complete words, phrases or even sentences.

And speech recognition by microcomputers is no more than a handful of years away. This year one manufacturer introduced a "hearing typewriter" that prints, with perfect spelling, what it hears. This machine has a vocabulary of 100,000 words — and accepts spoken input at the rate of 150 words a minute. Incredibly, it compares sounds to text in its memory eight times per second. What this means for individuals who are quadriplegic, for many people who are blind, and what it will mean soon for people who are deaf, once the machines become capable of understanding more than one voice at a time, can scarcely be described. First, though, costs must come down — and we must get the machines to the people who need them.

Today, it is not even necessary to "come to the office". In some cases, IBM's Kevin Riley and National Institute of Health's Rick Pilgrim are two examples of young men with quadriplegia who work from their homes by talking to their computers.

Increasingly, rehabilitation professionals are asking: "Does the employer really care whether fingers type words? Does it really matter whether ears hear them? And is is truly important whether eyes read them?" Employers, for their part, frequently surprise themselves by responding, emphatically: "No!"

Baby Boom/Baby Bust

Employers became accustomed during the 1960's, 1970's and early 1980's to having a large surplus of supply over demand: there were many more qualified jobseekers than jobs. Quite suddenly, that has changed.

We usually describe the "baby boom generation" as comprised of people born between the years of 1947 and 1964. A little arithmetic immediately tells us something of great importance to the labor market: the youngest baby boomers turned 22 in 1986. That is, most baby boomers already are in the labor force. In some states, notably oil-producing Texas and Oklahoma, the general economy turned weak in the mid 1980's. Elsewhere, however, the impact of the relatively small "baby bust" generation is being felt. In job-rich Massachusetts and New York's Long Island, the effect is dramatic. Faced with a sudden and acute lack of jobseekers, employers had to dust off ages-old strategies to recruit people to fill jobs. Bloomingdales found itself paying employees $50 just to bring a friend in for a job interview. Other companies paid the round-trip bus fares of workers willing to come in from far-flung communities. McDonald's, Burger King and other fast-food establishments discovered that they no longer could attract employees by offering minimum wage — and quickly raised pay by as much as 50%. Still other firms turned to a once-ignored group, older Americans, to fill part-time and part-season jobs.

The Massachusetts state government, faced with what was close to "zero unemployment", geared up to employ more than 28,000 welfare recipients.

An Opening - At Last?

Does all of this indicate that America is ready, for the first time since World War II, to employ large numbers of people with disabilities? The President's Committee believes that in many states it may well be — and we are prepared to respond.

The last time we had such a potentially favorable climate for employment of people with disabilities was during the mid 1940's, with many men overseas in battle. Now, as then, things still could go wrong — the economy may weaken nationwide, for example, making job prospects as poor throughout the nation as they now are in Oklahoma, Louisiana, and Texas. Technology may fail to keep its glowing promise. The country may decide that employment of people with disabilities is not as important as the President's Committee thinks it is.

Nonetheless, today we have a chance for a sustained growth in employment for people who are disabled. We have this opportunity for all the reasons discussed earlier and listed below:

- Life-safety dangers at work are sharply fewer in number in today's worksites;
- Today's jobs are more suitable than ever for people who are disabled;
- Technology increasingly is making disability irrelevant at the workplace; and
- Employers are more and more eager to find qualified workers, as the number of youth leaving schools for jobs continues to fall.

This immediately raises a question: "What about all those able-bodied people out there? Won't they enter the job market and take jobs that otherwise might go to individuals with disabilities?"

To answer that question, let us look at the results of a recent study by the Bureau of Labor Statistics. In 1983, the Bureau found that 89.6% of the 62,665,000 persons, aged 16 or over who were not in the labor force, did not want to work. These 56,161,000 individuals had different reasons for not seeking employment. Half (50.5%) were "keeping house", while others were retired, seriously ill or disabled. Of those who expressed a desire to work, but said they were not actively seeking employment at the time, 25.2% thought they could not get a job, 24.7% were in school, 21.7% were keeping house, and 12% were "ill or disabled".

This suggests what is in fact true: large numbers of people are not in the labor force. For reasons of their own, they are neither working nor seeking work. That is as true now as it always has been. Thus, the likelihood is that large numbers will not compete with disabled jobseekers for available positions.

The labor market has a history of absorbing large numbers of new workers as the economy expands. In 1950, only 18,408,000 women over 16 years of age were in the labor force, out of a total of 54,289,000 such women. By 1983, according to the Bureau of Labor Statistics, 48,646,000 women 16-and-over were in the labor force. As more and more women sought employment, the job market expanded to accommodate 30 million more female workers. To illustrate how staggering that growth was, consider that only 16,659,000 more men were working in 1983 than in 1950.*

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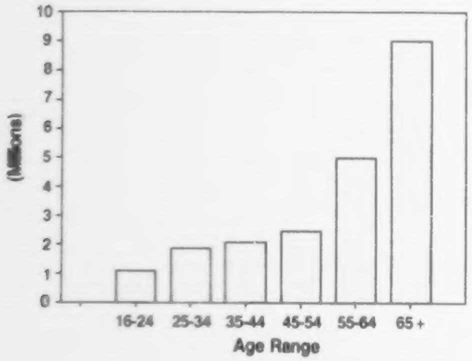
* 1985 Statistical Abstract of the United States, Table 664, Page 396. US Government Printing Office, 1985.

What happened was that societal values changed. In 1950, it was socially acceptable for women to remain out of the labor force; by 1983, the socially approved role for many women was a lifestyle that included employment. It was important to us that women be able to work. And the economy responded by generating enough jobs so that most women wanting employment could get it.

If the economy continues to expand throughout the 1980's, we can do for disabled people what we as a nation did for women: find sufficient numbers of job opportunities so that most disabled individuals who want to work can do so. It will take a national commitment to do the job: we as a country must say that this is a priority for us.

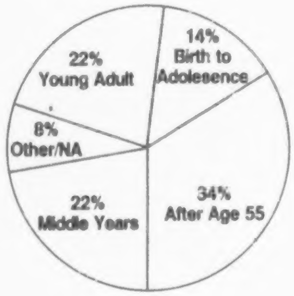
As bright as the picture potentially is, we must recognize the limitations that still face us. Employer concerns about hiring disabled people remain high in many industries. Some individuals with disabilities believe they are better off not working. The dazzling new technologies remain out of reach for poor persons with disabilities. Many persons who are disabled are close to retirement age. And a recession may greatly diminish opportunities for expansion in the job market. Then, too, there is only so much that a Federal agency as small as is the President's Committee can do to influence our nation's societal values and employment practices. But the important point now is that a great deal can be done — and we must grasp the opportunity.

Chart 2: DISABILITY AND AGE



Disability is something that happens to us as we live. It becomes more likely as we get older.
Source: U.S. Bureau of the Census, 1985.

Chart 3: AGE AT ONSET



Another look at disability and age.
Source: Data from Louis Harris and Associates, Inc., 1986.

THREE: People With Disabilities and Employment

What about people who are disabled themselves—are they prepared to respond to the emerging employment opportunities? The President's Committee is pleased to present some important information indicating that the answer to this vital question is, "Yes!"

Author Frank Bowe has advanced the "theory of thirds" to describe the population of 16-64 year old adults with disabilities.* As he notes, the "thirds" are not actually symetrical.

About three in every ten disabled adults (31.3%) are in the labor force. Another 41.2% receive Federal Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) benefits because of disability. And 25% are neither on payrolls nor on aid rolls. The 1985 Current Population Survey (CPS) upon which he reports does not include questions probing why some disabled adults work while others do not.

Fortunately, Louis Harris and Associates conducted a nationwide poll of disabled adults in late 1985 that helps us to understand more about the hopes, fears and lives of disabled adults.†

The Theory of the Thirds

For years, disability advocates have suffered from a lack of accurate statistical information. Now, for a change, we have the luxury of two nearly concurrent studies—one examining in detail the employment and economic status of adults with disabilities, and the other looking at an almost identical population, but this time asking probing, personal questions about beliefs, backgrounds, and barriers.

Beneficiaries. One persistent question about disabled adults over the past decade has been that of whether a majority really wants to work. The 1985 Current Population Survey (CPS), March Supplement, by the U.S. Census Bureau offers important insights into this issue. Thus, while 42% of disabled adults received SSDI or SSI benefits, the study shows that a large number of these individuals, in fact more than half (56.1%), were between 55 and 64 years of age; many were in early retirement. By contrast, just 12.2% of disabled 16-64 year old beneficiaries are in the prime working years, 35-44. Only 9.3% are 25-34 and 27.6% were veterans. In fact, 50.9% of all disabled males receiving benefits because of disability were veterans.

In America, veterans benefits frequently are linked to employability. As a result, many disabled veterans must earn a significant wage to offset potential benefit losses. However, it is more likely that disabled veterans seeking work fail to get jobs due to employer resistance to hiring them.

Of the 5,161,000 disabled persons aged 16-64 receiving SSDI or SSI because of disability, 2,893,000 are 55 to 64 years of age. And 1,425,000 persons, including some who are 55-64, are veterans. If we were to eliminate veterans and persons over 54 years old from the pool of individuals receiving benefits, we would discover that we have reduced the size of the receiving-benefits population by two-thirds.

The ostensible preference of many disabled people for benefits always has been rather puzzling. These individuals have to forego "substantial gainful activity"–level earnings; thus, they may make just $300 or so per month without jeopardizing their benefits. In fact, the average income from all sources of disabled persons receiving benefits was just $5,345 (median) and $7,610 (mean) in 1984. Twenty-nine percent live in poverty.

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* Bowe, F. Disabled In 1985: A Portrait of Disabled Adults. Hot Springs, AR: University of Arkansas, 1986.

† Louis Harris and Associates. Disabled Americans' Self Perceptions. New York: 1986.

Why do two million non-veteran, under-55 disabled persons accept these limitations on their lives? Without asking them directly, the best we can do is to speculate. Probably the most direct indicator is the fact that 84% of all beneficiaries with disabilities aged 16-64 are severely disabled, of whom half are 55-64. In other words, the combination of severe disability, which often imposes heavy medical care burdens, and near-retirement age probably makes many of these people feel that they cannot get a good job.

Labor Force Participants. Adults with disabilities in the second category, those who participate in the labor force, are on average much younger than are benefit recipients. Bowe also reports that, not surprisingly, those disabled adults who participate in the labor force are better educated than are those who do not. Four in ten of labor force participants are high school graduates, and one in every seven is a college graduate. They are also, however, less likely than are non-working persons with disabilities to be severely disabled. According to the 1985 Current Population Survey, only 10.2% of severely disabled adults of working age are in the labor force.

For people with disabilities, the evidence in the Current Population Survey on income of labor force participants is encouraging. Disabled adults received, from all sources, about twice as much as did disabled non-labor force participants. The median for disabled persons participating in the labor force was $11,553 in 1984 as against $14,514 for nondisabled labor force participants. The mean was $14,894 vs $17,434 for nondisabled adults. These income levels are 83% as much as those of nondisabled persons who participate in the labor force.

This is vital information. It shows that when people with disabilities persist in their efforts to get good jobs, they do nearly as well financially as do nondisabled people.

However, as Table 1 illustrates, not enough disabled people are at work. In fact, due largely to recessions in the 1970's and early 1980's, fewer work today than in 1970 or 1980.

"No Pay, No Aid." Earnings levels of workers with disabilities must seem especially enticing to the final "third" of the working-age disabled population—those receiving neither benefit checks nor pay checks. According to the 1985 CPS, the median income in 1984 from all sources of this 26.7% of the population was just $3,013; the mean was a slightly higher $3,755.

Women with disabilities in this third category—and they constitute fully 64% of all disabled persons in this group—had a median income of $2,222 and a mean income of $2,560.

All of this suggests that most people who are disabled probably want to work. To be sure, however, we should ask them directly. That is what Louis Harris and Associates did in late 1985.

Table 1

Labor-force Participation and Employment of Persons with Disabilities, Selected Years

[Numbers in Thousands]

	In Labor Force			Employed Previous Year		
Year	Total	Male	Female	Total	Male	Female
1970	4,938	3,592	1,346	4,581	3,327	1,254
1980	4,595	3,055	1,540	4,508	2,980	1,528
1985	3,847	2,353	1,494	4,366	2,626	1,740

Source: U.S. Bureau of the Census

The drop-off by disabled males is particularly striking. Although women with disabilities made some progress between 1970 and 1980, their gains were far more modest than were those of nondisabled females.

The Harris Study

In 1985, the National Council on the Handicapped, a presidentially appointed body of 15 persons, considered commissioning a nationwide poll to supplement a report they were required to give to Congress by February 1986. One member of the Council, New York's Jeremiah Milbank, Jr., took the initiative to arrange private financing through the International Center for the Disabled (ICD). Milbank and other Council members then worked with ICD to provide technical assistance to Louis Harris and Associates in planning the first ever nationwide poll of a random sample of disabled Americans.

The poll was conducted in December, 1985, and the results released in March, 1986. The Harris team called more than 16,000 randomly generated numbers in order to locate and interview 1,000 adults who are disabled. Each interview took approximately 30 minutes.

The Harris interviewers first assembled basic demographic information in order to describe the population. It is reassuring to statisticians that Harris found almost exactly what the Census Bureau reported in the same year—that two-thirds of the Americans who are disabled do not work. Harris also found, as did the Census Bureau, that the more severe the disability, the greater the likelihood that an individual was receiving benefits. There were many other points of confluence.

What happened is that although the Harris team and the Census Bureau workers talked with different disabled people, both used random sampling approaches, which, according to statistical theory, means that results of both studies are generalizable to the same universe of people—adults who are disabled. Both, too, were done in 1985. So, we have two portraits of the same population at about the same time.

But Harris asked some questions the Census Bureau did not ask—and the answers to these questions are highly revealing.

Age at Onset. In addition to inquiring about disability status, the Harris group asked persons being interviewed the age at which they became disabled. Thus, Harris was able to look separately at people who became disabled early in life, on the one hand, and those who became disabled later, on the other. The two groups were, it turns out, quite different.

Those who became disabled early in life were more likely to be working at the time of the study than were later disabled individuals. In fact, of all 16-64 year-old persons who were disabled and who were working, 20% became disabled before leaving adolescence, and an additional 41% became disabled early in adulthood.

By contrast, among all 16-64 year-old adults with disabilities who were not working, 31% became disabled in middle age, and another 23% became disabled after age 55.

Harris speculates—and the President's Committee agrees—that what was happening apparently is that people who became disabled early in life had adjusted to the disability and had gone on to have careers. People who lived most of their lives as nondisabled individuals and then became disabled in their 50's, however, seem to interpret disability as preventing them from continuing to work.

Whatever the reasons, the finding is a critically important one: early disabled people are better at finding and keeping jobs than the Census Bureau statistics seemed to indicate. That is, their success was "hidden" by the large numbers of later disabled persons who were out of the labor force. In this area, as in so many, the Harris results are encouraging for anyone interested in promoting employment of persons who are disabled.

The age-at-onset question also provided confirmation of Census Bureau reports: those who are out of the labor force are more likely to describe themselves as severely disabled than are those who participate in the labor force.

Self-perception. Harris asked the 1,000 persons with disabilities whether they considered themselves to be disabled. Overall, among those aged 16-64, 47% said, "Yes". The proportions were very different, however, between those who were working and those who were not. Among working persons who were disabled, a remarkable three out of every four (73%) said they did not consider themselves to be disabled. By contrast, six in every ten (59%) of those not working said they thought of themselves as disabled.

Harris defined respondents as disabled if they reported physical, sensory (hearing, vision), mental, emotional, speaking or learning disabilities, if they were limited in work or other activities due to a health condition or disability, or if they considered or believed other people would consider them to be disabled.

The President's Committee has long believed that individuals with disabilities who are successfully employed often tend to believe that they are not handicapped. For example, in explaining the data we reported in Disabled Adults In America (President's Committee, 1985), we said that there was no other way to interpret the figures except to recognize that when people who are disabled get jobs, keep them, and surmount obstacles in other aspects of their daily lives, they tend to regard their limitations as minor or non-handicapping. When asked by the Census Bureau or by Harris or any other pollster if he or she has a physical, mental or other health condition which has lasted six months or longer and which limits the amount or kind or work, school or other activities he or she can do, it is quite logical for a disabled person who no longer encounters major problems in these areas to respond, "No."

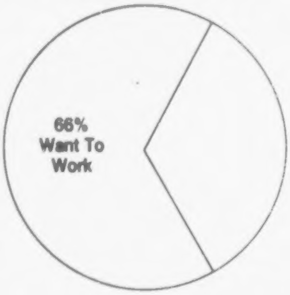
A similar indication of the same phenomenon emerged when Harris asked its 1,000 respondents with disabilities about satisfaction with their own lives. Eighty percent of all working people between the ages of 16 and 64 described themselves as "very satisfied" (48%) or "somewhat satisfied" (32%). By contrast, just 12% said they were "somewhat dissatisfied" and only 3% were "very dissatisfied".

Harris found a different picture when it asked the same question of non-working people who were disabled. Just 62% described themselves as "very satisfied" or "somewhat satisfied", while one-third (33%) said they were "somewhat dissatisfied" or "very dissatisfied".

This helps to confirm what we suggested earlier, while looking at the 1985 Current Population Survey data from the Census Bureau. Many persons with disabilities who are not now working are less than satisfied with their lives. But would they want to work?

Attitudes Toward Working. The Harris team asked working-age persons with disabilities who were unemployed at the time of the study, unable to work due to disability, retired, engaged in housekeeping or working as volunteers, whether or not they would take a job if one were available.

Chart 4: WANT TO WORK



Two-thirds of disabled adults without jobs say they want to work — including homemakers and persons over 65 years of age.
Source: Louis Harris and Associates, Inc., 1986.

Two in every three (66%) said they want to work. This high figure is especially impressive when it is recalled that those asked include retired individuals under 65, homemakers, and people who believe themselves to be severely disabled.

As a follow-up question to many of the same people, Harris asked respondents who were not working what the most important reasons for their current absence from the labor force. Not surprisingly, disability was cited by 78% as a major reason. More than half commented that their need for medical treatment was a factor. But most other key reasons are conditions we as a nation can do something about:

- Employer bias. 47% said employers did not recognize their ability to work full-time;
- Lack of knowledge: 40% said they could not find or did not know how to find full-time jobs;
- Training: 38% said they did not have the skills, education or training to get a full-time job;
- Transportation: 28% reported that lack of accessible transportation was a major barrier;
- Accommodations: 23% said that they needed special devices or equipment to work full-time.

Remarkably, only 18% said that the prospect of losing benefits was a major concern. This is particularly impressive in view of the fact that 70% of those receiving benefits told the Harris team that they would in fact lose benefits if they worked full-time.

And just 15% cited inability to arrange child care or the pressure of other family responsibilities.

Accommodations. The Harris team asked respondents who were working and those who had worked while disabled whether their employers made accommodations to their limitations. Only one-third answered that question affirmatively: 61% said that no accommodation was made or needed—35% said the employer made one or more accommodations, and four percent did not respond.

Again, we see an important implication for the President's Committee: It is vital that we get the message out to employers that they should make reasonable accommodations to the known limitations of their employees. And it is critical that we educate persons who are disabled about their right to reasonable accommodation. Where there are no rights to reasonable accommodation, we ought to undertake activities leading to establishment of such rights.

Knowledge About Government Services. When asked, only 60% of the 1,000 disabled Harris respondents expressed familiarity with vocational rehabilitation services—and just 13% had used them.

Only 31% expressed any familiarity with Section 504 of the Rehabilitation Act of 1973 (Public Law 93-112), arguably the most important civil rights statute enacted on behalf of people with disabilities.

From all of this, the President's Committee concludes that most disabled adults are ready, willing and able to work—if they are made more aware of their rights and of services available to them, and if employers are better informed about their responsibilities under law, about assistance available to them as employers, and about the potential of disabled people as workers.

Of America's working-age individuals with disabilities, just 4,366,000 worked full or part-time in 1984.

The Harris survey found that younger disabled persons were most likely to be willing to work—and least likely to regard their disabilities as serious obstacles to employment. That is, they generally were comfortable with their limitations, had learned how to deal with them, and were ready to pursue careers despite disabilities.

The 16-24 year old group also is the first to have benefited to any extent from the massive changes in special education and in higher education started by Section 504 of the Rehabilitation Act of 1973 and Public Law 94-142, the Education for All Handicapped Children Act. Today's 16 year old was five years old when Public Law 94-142 was enacted and seven when regulations for that law and for Section 504 were issued. Thus, individuals who are now 16 benefited for most of their elementary, secondary and postsecondary years from the changes these laws mandated. Today's 24 year-olds were, respectively, 13 and 15, and thus benefited from Section 504 and Public Law 94-142 only during their secondary and postsecondary years.

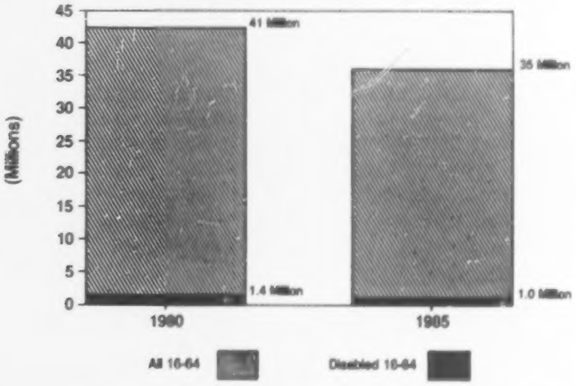
Although the years between 16 and 24 are often times of stress for many youth, it is important to recognize three other factors which are cause for optimism about the prospects that many disabled young people will be successful in their efforts to get good jobs. These are:

Assistance Begins. In recent years, the Federal Government has begun to focus considerable attention upon the special needs of "transition-age" disabled persons. More is needed. These individuals, who are at an age in which many are moving from schools to jobs, from parental supervision to lives on their own, and from institutional programs to community residence, usually are between the ages of 16 and 24, and thus are often eligible for daily special programs and for protection against discrimination under terms of Public Law 94-142 and Section 504. The U.S. Education Department launched several "transition" projects and targeted many grant programs to this population. In addition, the Rehabilitation Services Administration reported in its latest annual report to Congress that 37% of all persons rehabilitated were under 24 years of age—four times as many as the group's size would seem to indicate.

Less Competition. The first "baby bust" generation members are blessed by being few in number—and in following hard upon a "baby boom" generation that was huge in size. There are four million fewer 16-24 year-olds in 1986 than there were in 1980. Businesses that traditionally have hired young people are finding now that almost all the baby boomers are already in the labor market, that they have to resort to unusual measures to attract candidates for jobs. In this climate, disabled young people are more likely than are disabled youth in several generations to find employers open to hiring them.

Small Size. Not only are there fewer 16-24 year-olds in general, but the proportion of these individuals that is disabled is smaller than that of any other age range. While 10% of school students receive some special education programming, only one in every thirty-three 16-24 year-olds has a work disability, according to the U.S. Bureau of the Census. The rate of work disability in this age group, then, is just 2.9%. In fact, there are only slightly more than one million work-disabled transition-age individuals in the United States today—and they represent just 8.3% of the working-age population of persons with disabilities. Thus, whatever we as a nation do for employment of this population is magnified in its impact because the benefits are spread over a relatively small group of persons—each of whom receives relatively more than otherwise would be the case.

Chart 5: BOOM TO BUST



As the baby boom generation aged out of the 16-24 age range, transition-age youth with and without disabilities have become fewer in number, reducing competition for jobs. Source: U.S. Bureau of the Census, 1980, 1985.

Recommendations

1. We should encourage these young people to take full advantage of higher education opportunities. Today, thousands of colleges and universities coast to coast are ready, willing and able to accommodate their needs. Like virtually every other segment of society that focuses upon young people, higher education is confronted by a dramatically smaller 16-24 year-old population. To keep their enrollments up, many colleges are expanding services to disabled students. And because of Section 504, they are required to admit and provide supportive services for any disabled students who meet their admission criteria and demonstrate that, with the accommodations, they can do the assigned work.

2. We should encourage these people not to rely solely upon government. Unfortunately, in many states, disabled youth at state-operated education programs and in some local schools are automatically enrolled in Supplemental Security Income (SSI) programs—which sends the wrong message to impressionable 14 or 16 year-old minds. At the least, such efforts should be augmented by employment-related endeavors.

3. We should urge disabled youth with potential for good careers to forego the readily available minimum wage jobs and to continue to search for jobs with a future.

4. While disabled 16-24 year-olds are better acquainted with Section 504 and Public Law 94-142 than are their elders—these laws, after all, are part of their daily lives—we must nonetheless educate them about how to make maximum use of rights and services.

5. For other disabled individuals, we should be encouraging employers of young people to emulate innovative programs such as McDonald's "McJobs" effort as ways to meet recruitment needs.

6. We must find ways to channel the energies and concerns of parents into activities that support their children's work preparation.

FIVE: The Middle Group

More than half of all disabled 16-64 year-olds are in the "middle group" of persons aged 25-54. They are neither young enough to benefit from transition services nor old enough to be eligible for early retirement.

Most of these individuals "made it on their own" without the benefits of Section 504 of Public Law 94-142. The youngest were juniors in high school before implementing regulations for these laws appeared—and the oldest already were 45 in 1977. The "middle group", then, in many cases grew up with an image in their minds of disability as "something wrong with you", something stigmatizing, something associated with charity, nursing, and a life of dependency.

A majority were not disabled until well into working age. As the Harris survey found, people who become disabled as adults tend to cope less well with limitations—and to regard them as more debilitating—than is the case with people who are born disabled or become disabled in childhood or adolescence. People who become disabled in adulthood are markedly less satisfied with their lives than are early disabled people, according to the Harris study. Often, an entire lifestyle changes, expecially if counseling and other rehabilitation services are not made available.

In many ways, then, the "middle group" is in need of more help than are younger disabled individuals. Yet less assistance is made available.

Sixty percent of the middle group is out of the labor force. These nearly four million disabled people have needs that are very different from those of younger or older individuals with disabilities—needs we are seldom prepared to meet.

The major issues with respect to these individuals, the President's Committee believes, are:

Advancement. It is during these "peak" employment years that most people make their move from "a job" to "a career". That is, some succeed in moving up to better paying jobs with more responsibility; others, however, do not.

Our society offers very little in the way of support for people with disabilities. Although the Rehabilitation Act of 1973, as amended, permits state vocational rehabilitation agencies to provide follow-up services to disabled persons desiring to get better jobs, fiscal realities in recent years have forced most agencies to attend much more to disabled individuals looking for work. Private rehabilitation associations and groups, too, are hard pressed for funds. They also tend to focus much more upon the needs of unemployed individuals.

Even looking at the disability press and at mass media stories, we find a dearth of support for people looking to upgrade their level of employment. Rather, most stories highlight individuals going through medical and physical restoration and those looking for, and landing, their first jobs.

The "myths" or ethos, in effect, is "Once you've found a job, we can chalk you up as a 'success' and turn to the needs of others". The President's Committee believes that this limited vision of the potential of disabled people is seriously erroneous—and intends to focus upon career advancement for people with disabilities.

Awareness. Many working disabled persons have had little exposure to disability rights. Few in the 25-54 age range are aware of Section 503, which requires affirmative action by contractors who do business with the Federal Government. And even fewer know about state and local nondiscrimination and affirmative action laws protecting them.

Peer Support. In a few companies, but to date only in very few, disabled employees have joined together to provide peer counseling and other supportive services. At New England Telephone, for example, it was not until 1986 that the company's 400 disabled workers formed an employee association similiar to those women and blacks had formed decades earlier.

Equally critical, there is no magazine or other periodical providing to disabled workers the support offered to women by such publications as Working Women and to blacks by Ebony.

The President's Committee recognizes this gap and intends to talk with working disabled people to find ways to fill it.

Job Retention. We noted earlier in this publication that just 2.9% of all youth aged 16-24 are disabled. By the time disabled persons reach the 45-54 age range, 10.7% are disabled, or three times as many. For most disabled persons in the middle group of persons aged 25-54, disability is something that occurred after they had started to work. For some, few adjustments are needed to permit them to come back to work. For others, however, accommodations are required in order to return to the job held prior to the disabling accident or illness. For still others, return to the previous job is not possible.

In our society, workers' compensation programs are the service of first resort for many newly disabled employees. But workers' compensation laws, most of which were written decades ago and seldom updated since, actually discourage many disabled persons from seeking and taking advantage of vocational rehabilitation services. And workers' compensation benefits sometimes actually exceed after tax earnings before onset of disability—thus discouraging rapid return to work.

The President's Committee believes that the nation's Governor's Committees have a role to play in helping to facilitate job retention. Because workers' compensation laws are all state-based statutes, we need state-based initiatives to modernize these programs.

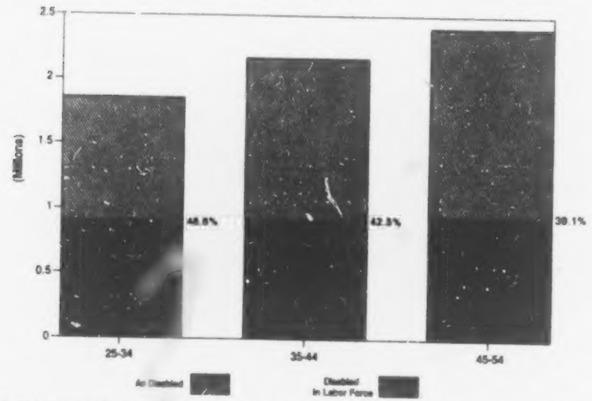
Outreach and Recruitment. Although the Federal Government has provided extensive assistance for transition-age disabled persons, there are far more disabled individuals in the middle group who need help in getting onto payrolls. In fact, participation in the labor force declines steadily throughout the age levels in this group, largely because so many of its members are newly disabled.

The numbers are sobering. Of the 1,853,000 disabled adults aged 25-34, 900,000 are in the labor force, for a 48.6% rate. In the next range, that of persons aged 35-44, just 921,000 of the 2,168,000 disabled adults, or 42.5% participate in the labor force. And among disabled persons in the 45-54 age range, only 749,000 of the 2,407,000, or barely 31.1%, are in the labor force.

Vocational rehabilitation programs, the most logical source of assistance for these people, expend far more resources upon under-24 individuals than on any older age group. Of all persons under 65 rehabilitated in 1981-1982, the most recent year for which full data are available as this is written, 37% are under age 24. By contrast, 27% were aged 25-34, 16.7% were in the 35-44 age range, and 12.1% were 45-54 years old.

The President's Committee believes that it is time we recognized that six times as many disabled people who are not in the nation's labor force are in the middle group as in the transition-age group—and focus our resources accordingly.

Chart 6: SLIPPING OUT OF THE LABOR FORCE



Although more people are disabled in each succeeding age range, participation by disabled persons in the labor force steadily declines throughout the "middle years." Source: U.S. Bureau of the Census, 1985.

Recommendations

1. We need to help private, local, and state counseling and vocational training programs adapt their offerings to meet the needs of this middle group of 6,237,000 disabled persons. The highest priorities for the four million people out of the labor force seem to be counseling, and medical restoration services immediately after onset, followed by rapid re-training to help the individual continue the same kind of work despite disability or to learn different vocational skillls.

2. It is urgent that we as a nation get the word across to employers that disabled individuals have potential. Huge numbers of workers with disabilities have been "stuck" in jobs because employers do not recognize that they can be trained for and placed in better jobs. In part, this is our fault, those of us in the disability community, because our message to date to employers has been one of hiring new jobseekers with disabilities—not advancing those already on the payroll. The President's Committee, for example, each year has honored "employers of the year" more for their hiring than for their internal movement achievements. Perhaps it is time for a new award category.

3. Workers' compensation laws in the several states need to be revamped to remove some serious disincentives to return to work. Artificial obstacles between state workers' compensation boards and state vocational rehabilitation agencies must be removed.

4. Publications such as the President's Committee's Disabled USA need to carry more stories offering self-help to working disabled people. In particular, these magazines could play a valuable role by focusing upon support groups in local communities and in corporations, showing disabled workers how others have organized to help themselves at the work place. And stories explaining, in lay language, the meaning of Sections 503 and 504 are needed on a continuing basis.

Table 2

Distribution by Age of U.S., Disabled 16-64 Year-Old Persons Not Living in Institutions, 1985

Age Range	U.S. Population	Disabled Population	Proportion Disabled
16-24	35,062,000	1,026,000	2.9%
25-34	40,858,000	1,852,000	4.5%
35-44	31,299,000	2,168,000	6.9%
45-54	22,398,000	2,407,000	10.7%
55-64	22,151,000	4,837,000	21.8%

Source: 1985 Current Population Survey, U.S. Bureau of the Census

SIX: Women and Minority Group Members

In recent years, the President's Committee has drawn national attention to the special needs of women, blacks and persons of Hispanic origin who are disabled. The Committee has published special reports on each of these segments of the population of people with disabilities. The Committee hosted major conferences bringing together representatives of groups specializing in meeting the needs of women, blacks and Hispanics, with experts on rehabilitation and disabled consumers, to fashion new networks to meet the range of needs these people present.

Our work in these areas, though, is just beginning.

Women

Females comprise 49% of all working age Americans with disabilities—and 53% of those out of the labor force. In fact, just one woman with a disability in every five among the working-age population has a job. That contrasts to more than 60% of all nondisabled women between 16 and 64 years of age—and 37% of 16-64 men with disabilties.

We can describe the working-age population who are disabled women using Bowe's "theory of thirds": 25% of disabled females aged 16-64 are in the labor force, 40% are receiving SSDI or SSI benefits because of disability, and 35% are neither on payrolls nor on aid rolls.

Women with disabilities in the labor force are much less likely to be married (44%) than are nondisabled women participating in the labor-force (56%).

Among working-age women with disabilities who received SSDI or SSI benefits because of disability, just 38% are married. These women are, on the average, much older than disabled women labor force participants: 59% are between the ages of 55 and 64, as compared to just 22% of those in the labor force. The median income from all sources in 1984 for female benefiaries was $4,495; the mean was $5,916. Not surprisingly, 34% lived in poverty.

The median income, from all sources, in 1984 for disabled labor-force participants who were women was $7,857; the mean was $9,868. A total of 21% lived in poverty.

In the third category, especially, we see evidence that women with disabilities are in need of urgent help. They constitute 64% of all disabled working-age persons who are neither on payrolls nor on aid rolls. Six in every ten are married. Their median income from all sources in 1984 was $2,222; the mean was $2,560. While many relied upon their husbands income, 36% lived in poverty.

Women with disabilities have not participated in the "women's revolution" that saw 30 million women enter the labor force over the past two decades. Indeed, fewer are in the labor force today than in 1980.

Blacks

According to the 1985 Current Population Survey there are 2,175,000 blacks who are disabled between the ages of 16 and 64 in the United States. They represent 18% of all working-age persons with disabilities, despite the fact that in the general population they constitute just 11.5%. Their overrepresentation among persons with disabilities reflects the fact that disability occurs more often among blacks than among persons of any other race.

Using the framework of the "Theory of thirds", we see that just 22% of disabled blacks of working-age are in the labor force. Among black men, the proportion is 25%, and among black women it is 20%. Their median imcome from all sources in 1984 was $6,954; the mean was $8,670. Thirty-three percent lived in poverty.

Another 49% were in the second category, that of persons receiving SSDI or SSI benefits because of disability. That is the highest proportion by race in the disabled population. Their median income from all sources in 1984 was $4,239; the mean was $5,249. A total of 45% lived in poverty.

In the final "third," we find that 29% of all blacks with disabilities are neither on payrolls nor on aid rolls. Their median income from all sources in 1984 was $2,915; the mean was $2,446. Most of these blacks were women (61%). Of these women just 28% were married. Sixty-two percent lived in poverty. The 628,000 disabled blacks in this third category are the most desparately in need of all members of the disabled population.

Hispanics

Persons of Hispanic origin may be of any race. In America, the population of disabled individuals in this category number 863,000. They comprise seven percent of all disabled working-age persons.

Individuals of Hispanic origin who are disabled fall into the three categories we have been discussing as follows: 26% are in the labor force, 43% are on SSDI or SSI rolls because of disability, and 31% are neither on aid rolls nor on payrolls

Three in ten (30%) of disabled Hispanic men and 21% of the women participated in the labor force. Among those in the labor force, the median income in 1984 was $8,165; the mean was $10,266. A total of 24% lived in poverty.

In the second category, that of disabled Hispanics who receive SSDI or SSI benefits because of disability, we find 47% of all disabled Hispanic males and 39% of the females. The median income of disabled Hispanics in this category in 1984 was $4,457; the mean was $5,702. A total of 40% lived in poverty despite receiving benefits.

Finally, 22.9% of disabled Hispanic males and 40% of the females were neither on payrolls or aid rolls. Their median income from all sources in 1984 was $3,337; the mean was $2,691. A total of 53% lived in poverty.

Recommendations

1. Women, blacks and persons of Hispanic origin all have national, state and local organizations advocating on their behalf. The President's Committee intends to work with the National Organization for Women (NOW), the National Association for the Advancement of Colored People (NAACP), and similar groups to increase attention to disability issues on the agendas of these organizations. We will also work with Handicapped Organized Women (HOW) and other groups representing segments of the disabled poplulation. The Committee recommends that Governor's and Mayor's committees take similar action on the state and local levels.

2. The disability advocacy organizations have, in general, tended to be dominated by white males. The movement has been less than successful in attracting blacks and Hispanics in particular to its ranks. For whatever reasons this state of affairs exists, a change is long overdue. We must urge organizations representing deaf, blind, retarded, physically disabled and other handicapped persons to make special efforts to recruit women and members of minority groups.

3. In part as a function of what we have just observed about the "white" nature of disability rights efforts, and in part because of ethnic group indentification processes, many miniority group disabled persons turn for help first to organizations serving persons of their own race. We need to acquaint these organizations such as the National Urban League and Push-Excel, with the needs of their constituents who are disabled.

4. Particularly with respect to women who are disabled, societal attitudes need to be changed. Apparently, in today's America, it is "normal" and "acceptable" for most women, including mothers of young children, to work—but it is normal and acceptable for disabled women to depend upon others. The President's Committee believes that women with disabilities are equally as capable of independence and of designing their own lifestyles as are nondisabled women—or men. We must make a concerted effort to alter society's view that disabled women are "to be cared for" and construct, in its place, an image of women who can, if they wish, achieve to the full limits of their abilities.

SEVEN: Disabled Veterans

According to the March, 1985 Current Population Survey by the US Bureau of the Census, there are 3,015,000 veterans of working age (16-64) in America who have work disablities. Virtually all of them are men. These three million disabled veterans include 1,281,000 World War II veterans (42.5% of the total), 767,000 veterans of the Vietnam Era (25.4%), 581,000 Korean Conflict veterans (19.3%), and 385,000 veterans of other conflicts (12.8%).

Veterans represent one in every four persons with disabilities in the working-age populations, or 24.5%. Of all males who are disabled, 47.7%, or almost half, are veterans.

One month later, in April, 1985, the Census Bureau again looked at the population of disabled veterans as a supplement to that month's Current Population Survey. The results, analyzed by the US Labor Department's Bureau of Labor Statistics, showed that 2.5 million veterans of working age reported service-connected disabilities. These individuals had a 6.7% unemployment rate. Of those veterans with service-connected disabilities who served in Vietnam, 9.2% were unemployed, the highest rate among all veterans in the study.

One-third of all employed service-connected Vietnam Era veterans had jobs in Federal, state or local governments. This likely reflects affirmative action or veterans' preference practices in the public sector—and less pervasive equal opportunity in the private sector. To place the proportion into context, consider that just 15% of all workers have jobs in government. Among individuals with disabilities who have jobs, 17.6% work for Federal, state or local governments.

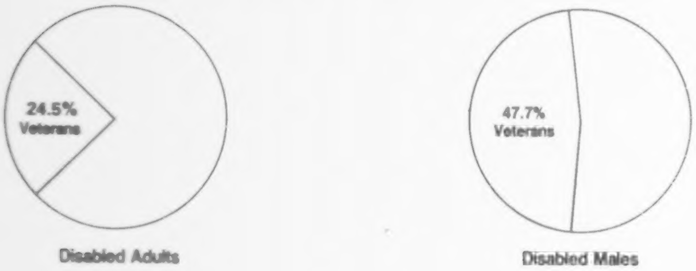
During 1985 and early 1986, members of the President's Committee on Disabled Veterans traveled to eight cities to interview disabled veterans, advocates, service providers, and government officials to indentify the major concerns of veterans with disabilities. Serving on the Committee are representatives from Disabled American Veterans, Blinded Veterans Association, The American Legion, AMVETS, Paralyzed Veterans of America, and Vietnam Veterans of America, among others. Federal agencies including the Veterans Administration, the Labor Department, and others provide liaison to the Committee. As we reported in Employment and Disabled Veterans: A Blueprints for Action, the single largest obstacle to better lives for disabled veterans is the lack of coordination among service providers. This is one reason why many Federal initiatives on behalf of disabled veterans have had disappointing results.

Recommendations

1. The President's Committee believes that organizations representing disabled veterans and those advocating for other persons with disabilities need to join forces to improve coordination of services for all individuals who are disabled. The fact that half of all working-age men with disabilities are veterans—and that disabled veterans comprise one-quarter of all disabled persons in the 16-64 age range—needs to be communicated to organizations working on behalf of people with disabilites. The common concerns between veterans and non veterans who are disabled far outnumber the differences.

2. The Veterans Jobs Training Act and other veterans employment programs have great potential. We found to reach that potential, however, we must improve inter-

Chart 7: DISABLED VETERANS



Disabled veterans number more than 3,000,000 — and represent almost half of all disabled men in this country.
Source: U.S. Bureau of the Census, 1985.

agency coordination. The Committee on Disabled Veterans found, in city after city, that officials of one agency were unversed even in the most basic aspects of other agencies' programs for the same population. The Committee's hearings also revealed that employers are perplexed by the "maze" of different forms and program requirements for this program and for other Federal and state initiatives intended to help disabled veterans.

3. Probably the single greatest barrier facing veterans with disabilties, after inter-agency coordination or even on a par with it, are negative public attitudes toward this group. Employers have particularly biased views about Vietnam Era veterans with or without disabilities. Working with organizations representing veterans and with both the Labor Department and the Veterans Administration, the President's Committee intends to find ways to combat these negative attitudes.

EIGHT: The 55-64 Group

A total of 4,837,000 persons aged 55-64 are disabled. These people represent 21.8% of all Americans in that age range. In fact, they constitute 39% of all working age (16-64 years old) disabled individuals in the nation. That is the single largest age group within the under-65 population.

Early Retirement. It is also where the "disability problem" is mushrooming most alarmingly. In the United States, Sweden, United Kingdom, Canada, Denmark, and other nations, growing numbers of individuals 55-64 years old are being "early retired" due to disability—and are falling onto social security rolls, according to a study just completed for the U.S. Social Security Administration by Rehabilitation International, a private group in New York City.

To date, the 1980's have been characterized by widespread early retirement. Companies forced by economic conditions, particularly foreign competition, to "downsize" often have done so by offering older employees the option to retire early. In April, 1986, for example, a senior General motors official stated that the company planned to eliminate one in every four salaried jobs in the North American Car Group by 1990, mostly by early retirment and attrition. According to a front-page story in the Washington Post, AT&T has cut 56,000 of its 380,000 jobs since 1980; 24,000 persons have been offered as much as $22,000 in cash, continued post-retirement medical benefits, and other inducements to retire early. Companies such as Xerox, Control Data Corporation, Kodak, and many others have early-retired hundreds of thousands of people.

In large part because of the fact that "severely disabled" was defined by the U.S. Bureau of the Census to include persons who were under 65 but received SSI or were covered by Medicare, a stunning 62.8% of all disabled 55-64 year-olds were classified as severely disabled. Of this group, only 5.2% participated in the labor force, or about one in every twenty. A total of 76.1% received SSDI or SSI because of disability, or three in every four. Just under one in five (18.7%) were neither on payrolls nor on aid rolls.

The single largest obstacle to better lives for disabled veterans is the lack of co-ordination among service providers.

Attitudes. The Harris study helps us to understand why so very few disabled persons aged 55-64 work. In large part, the answer seems to be that disability, combined with the fact that "retirement age" is approaching and the fact that disability benefits are available, is seen differently by older persons than by younger individuals.

For example, 56% of disabled persons aged 55-64 told the Harris pollsters that disability prevented them from getting around in the community. The proportion among 16-34 year-old disabled persons in the study was just 39%. Asked a similar question—whether disability has prevented them from reaching their potential as independent, fully realized human beings—61% of those ages 55-64 said, "Yes", as against half of the 16-34 year-old group.

Asked whether they were, in general, "satisfied" with their lives, 28% of those aged 55-64 expressed some degree of dissatisfaction, as against 17% of the younger 16-34 group.

Education. The 55-64 year-old group has received something of a "bum rap" for being poorly educated as compared to younger disabled people. According to the 1985 Current Population Survey, education attainment is comparable among 55-64 year-olds as contrasted to younger disabled individuals. Thirty-one percent have a high school degree, nine percent have at least some college, and seven percent are college graduates. Even among severely disabled persons aged 55-64, 28.3% have a high school diploma, 7.8% have attended at least one year of college, and 5.3% are college graduates. These figures are not appreciably different from those of younger disabled or severely disabled individuals.

Awareness. What is different is the familiarity of the 55-64 age group with civil rights of persons with disabilities. According to the Harris study, barely eight percent of these persons said they were "very familiar" with Section 504. One in four (24%) said they were "somewhat familiar" with this statute, which has been called "the civil rights act for disabled people". By contrast, 31% said they were "not too familiar" and 36% said they were "not at all familiar" with Section 504.

In part because of their lack of awareness of the disability rights movement, just 45% of disabled 55-64 year-olds believe that disabled persons constitute a minority group such as blacks and women are. That is lower than the 54% of 16-34 year-old disabled persons who hold this view.

In fact, as recently as 1960, 81% of all men aged 60-64 were in the labor force. It was 83% as recently as 1970. By 1985, the proportion was down to 62%. Even among 55-64 year-olds, the rate in 1985 was just 68% - and the U.S. Bureau of Labor Statistics expects it to be 64% by 1995.

Disability in the 55-64 Group. Within this country, according to the Harris study, 37% of all disabled persons became disabled after age 55. The 1,000 individuals in Harris' random sample included persons of all ages, not just working age.

Those in the sample who became disabled after reaching age 55 were markedly poorer than were those who were disabled at birth or became disabled by adolescence. While 21% of those with early onset had household incomes (including earnings of others living in the household) between $15,001 and $25,000, just 13% of the late onset group did. Eighteen percent or almost as many early-onset disabled persons had incomes in the $25,001 to $35,000 range, as against just 9% of the late-onset group. In the $35,000-and-over income category were just 5% of the late-onset group as compared to 19% of the early-onset segment.

Using Bowe's "theory of thirds" as a framework, we see that just 17.8% of disabled persons aged 55-64 participated in the labor force, according to the 1985 Current Population Survey. That is fewer than one in five. The proportion receiving SSDI or SSI because of disability was a remarkable 59.8% — or six in every ten. A total of 22.4% were neither on payrolls or on aid rolls, or better than one in five.

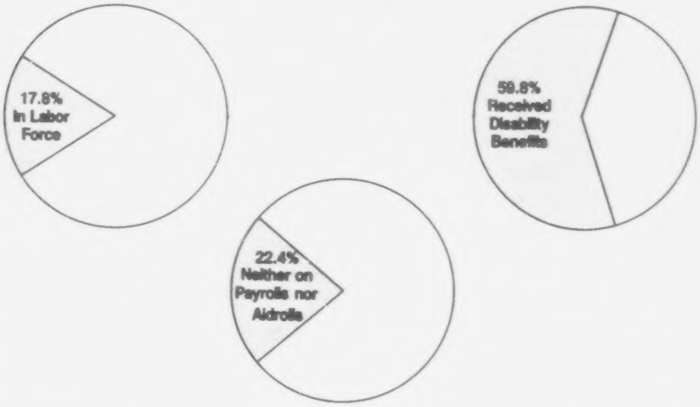
Recommendations

1. The President's Committee believes that far greater attention should be paid to the needs of older disabled persons for jobs. Those in the 55-64 age group comprise four in every ten disabled individuals of working age. Yet, they are receiving less attention than are the 8.3% of disabled persons who are in the 16-24 age range.

2. The Committee believes that disability benefits are not the best options available to people who become disabled in their late 40's and early 50's. At a time when life expectancy for individuals who become 55 has reached the high 70's, we need to look seriously at the employment potential of these "older" workers. One solution that deserves study: helping older disabled people to compete for, and get, the jobs that employers have available but are finding it difficult to fill because there are so few young people just entering the job market.

3. The President's Committee believes that early retirement is an issue that must be faced by disability advocates. We need to consider carefully whether early retirement is a direction in which our country should be moving. While the immediate savings to employers who are

Chart 8: THEORY OF THIRDS - 55-64 GROUP



Disabled persons aged 55-64 tend to be out of the labor force — and six in ten receive benefits because of disability.
Source: U.S. Bureau of the Census, 1985.

downsizing may be attractive, we believe that companies should be educated to appreciate the longer-term costs. Otherwise, more and more disabled persons in their 50's will be forced to retire early.

4. We need some way to help people who have worked for one employer for many years — as a large bulk of the 55-64 population has — to understand that it is not as easy as most think to get another job. The facts show that when older persons accept early retirement from one company thinking that they can supplement their benefits by working somewhere else, these individuals frequently are bitterly disappointed.

5. The President's Committee is concerned that the popular culture shapes the thinking of older disabled persons in such a way as to make them think retirement is the only option. No one is telling them about their rights under Sections 503 and 504. We need to work with the American Association of Retired Persons and similar groups to get the word out.

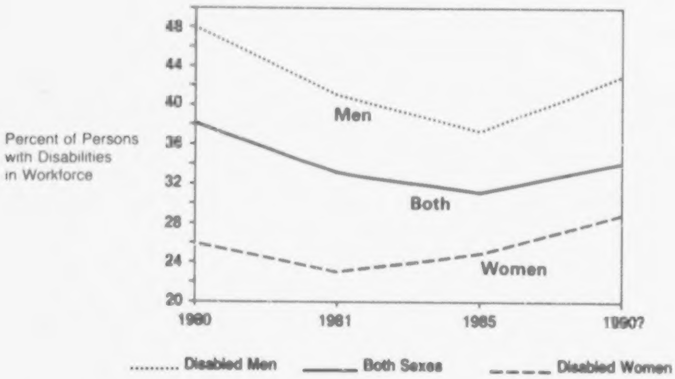
Table 3

Labor Force Participation Rates, by Age Ranges, of Persons with Disabilities, 1985

Age Range	Number Participating	Percent Participating
16-24	417,000	40.6%
25-34	900,000	48.6%
35-44	921,000	42.5%
45-54	749,000	31.1%
55-64	859,000	17.8%

Source. 1985 Current Population Survey, U.S. Bureau of the Census

Chart 9: CAN WE COME BACK?



Labor force participation by disabled persons has been dropped so far in this decade — can we halt and then reverse the trend?
Source: U.S. Bureau of the Census, 1980, 1981, 1985.

As the President's Committee looks to its 40th anniversary in 1987 and beyond, it will be relying heavily upon its thousands of unpaid volunteers, acting through Governor's and Mayor's committees as well as through its committees and task forces to confront the challenges ahead. Even with their help, we must set priorities for action. What follows is a "short list" of goals we believe are important:

- Awakening America to the vast potential of its millions of citizens with disabilities to be independent, self-sufficient individuals. This has long been an objective of the President's Committee - but it is a continuing task, one we must never neglect.
- Enhancing positive attitudes toward acceptance of persons with disabilities remains an urgent need. As President's Committee staff member Mary Jane Owen has noted, disability is something that occurs to people in the normal course of their lives. We accept risks as a part of living full and rewarding lives and should accept disability as a quite normal consequence of taking these risks.
- Just as the women's revolution leaders stressed that improving women's attitudes toward themselves was a *sine qua non* of social change, so too must we help people with disabilities, especially those who become disabled in adulthood and in later years, to see themselves as continuing to be important, powerful, and worthwhile human beings and to seek employment commensurate with their abilities and interests.
- We need to help people with disabilities gain a sense of common identity. As Harlan Hahn, a Professor of Political Science at the University of Southern California, has commented, a political identity as members of a minority group is essential if people with disabilities are to make further progress in civil rights.
- Finally, on this "short list" of goals, we place the need to make employers more aware of the economic and social consequences of their practices in employment. These are the same employers who have hired 30 million women over the past 35 years because they share the view of these women that they could and should, work. A similar "miracle" could follow if employers become convinced that people with disabilities can contribute to their business.

Awakening America to the vast potential of its millions of citizens with disabilities to be independent, self-sufficient individuals.

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Senator HARKIN. Thank you. It is always a pleasure and an honor to have you here. I remember when you were here last year—was it last year?

Mr. RUSSELL. Last January.

Senator HARKIN. Last January. Not in your statement, Humphrey, but in the draft report of this current study—by the way, when was the study completed?

Mr. TAYLOR. When was it completed?

Senator HARKIN. Yes.

Mr. TAYLOR. The field work was completed about four months ago.

Senator HARKIN. The draft report, and I will quote, said "Large majorities of top managers, 72 percent, EEO officers, 76 percent, and department heads and line managers, 8 percent, feel that disabled people often encounter job discrimination from employers." In other words, the top managers stuck in those companies are saying that the disabled encounter job discrimination from themselves. I guess that is what they are saying, from their companies that they work for. Am I interpreting that correctly.

Mr. TAYLOR. Not necessarily referring to their own companies. I think it is a general perception of the marketplace. If I may, I would like to kind of add a wrinkle to that. I think that in one sense that answer is encouraging in that it shows at least a willingness to recognize the problem and maybe a willingness to deal with it.

Running through our data, we get the feeling that most employers would genuinely be willing to do more. If they were incented they would be glad to do so, but it is such a low priority that they really do not give it much thought at the moment.

Senator HARKIN. But if it has been shown that disabled people work hard, they are very productive, they want to work, they can do the jobs, then why would they need incentives? There may be some support that is needed, but—

Mr. TAYLOR. I guess because of the hundreds of things that they think of every week, every day, every month, hiring disabled people is very, very low on their list of priorities. Nobody has given them a kick in the pants, nobody has said wake up, you are going to do better.

Senator HARKIN. I just wonder what the key factors are that lead to this discrimination, just a feeling that perhaps as employers they just have to do more, they have to pay more attention to disabled people, that it would detract from their operating the company or managing that segment? Have you delved into that? The report says that everyone feels that the employers discriminate against them.

Mr. TAYLOR. I must say that looking at all of the data, I do not believe that that is a major barrier, nor indeed do most of the disabled people feel that that is the major barrier. The major barriers seem to be the fact that they are poorly educated, poorly qualified, and therefore have less to offer the employer in many cases than many of the non-disabled job applicants against whom they are competing.

Senator HARKIN. I remember a conversation I had once a long time ago, a very long time ago—and I will have more to say about this at some other point—and it concerned my brother who is deaf. He went to work with one small company in Iowa, the man who owned this company went out of his way to hire the handicapped. This is back in the early fifties. He hired a bunch of deaf people. I do not know, he must have hired eight, nine, ten, out of a work force of maybe 150.

I remember I came home from the service at the time and he had worked there for ten years and had not been late one day or had not missed one day of work. Mr. Delavan always had a big Christmas party and he gave him a gold watch inscribed and all that kind of stuff. I was talking with him—this is before my conscience had been raised about the problems of the handicapped, and I said to him that it was interesting that he would hire all of these deaf people. And I remember him saying to me that one of the biggest problems he had was in getting his workers in the plant to overcome their uncomfortableness, they felt uncomfortable around these people.

I had never thought about that. I had always been comfortable around my brother, you see, but I never thought that people might feel uncomfortable and it just always stuck with me, and I wonder if there is something in this. It is only one thing that happened to me one time, but I have thought about that oftentimes. And now, looking at this and saying that there is discrimination against the unemployed, I wonder if these top managers might not feel, well, I do not want to bother the rest of my workers, I do not want them to feel uncomfortable, that they might have to work along side someone who is disabled.

Have you ever looked at anything like that?

Mr. Taylor. Yes, we have some evidence of that in both of these surveys. When I say that something is not a major barrier, I do not mean to imply that is not an important barrier. Clearly there is discrimination, whether conscious or whether because of embarrassment and discomfort and an inability to know how to cope with the situation, and therefore a tendency to avoid it. It is I am sure an important barrier and I did not mean to imply by my earlier remarks that we should minimize it.

Senator Harkin. Well, then it is really a leadership problem among top managers and CEOs, it is really a leadership problem.

You testified that employers believe that the two most potentially effective proposals for increasing employment would be to establish the direct training and recruiting programs and having companies provide internships or part-time jobs. It seems to me that we have in the recent past done a lot of this. We have tried to provide incentive programs, special education program development, incentives, and things like that, but there is still a feeling in the education and rehabilitation community that we are still lacking, that it just has not moved ahead and that, really, I will be quite frank with you, that employers have not done much in the cooperative area of meeting the government half-way.

Would you comment on that?

Mr. Taylor. Yes, Senator. In our first survey of disabled people, one of the most encouraging findings was the overwhelming agreement amongst a great majority of disabled Americans that the things have improved in this country a great deal during the past ten years or so, and furthermore that the Federal Government deserves a great deal of credit for that. This is one area where even critics of Federal Government action I think must accept that the Federal Government has made a tremendous and very positive impact.

Having said that, it is clear from the data that we have still got an enormous way to go before we can even begin to feel comfortable about the quality of life for most disabled people of this country, and I would agree with your point that employers have done much less than the Federal Government.

Senator HARKIN. Again, I agree with you that we have come a long way, though, we really have.

Thank you very much.

Senator Simon?

Senator SIMON. Thank you, Mr. Chairman. Just a couple of quick comments and then a question. I want to question each of you.

I saw the Associated Press story buried in the back-end of the papers the other day that said for the first time the average Japanese worker is now making more than the average American worker.

In 1950, the average Japanese worker was making 5 percent as much as the average American worker. Japan has invested in her people and used her human resources. One of the great largely untapped human resources we have in this country are Americans with disabilities. Mr. Taylor, in one sentence in your statement I think you are absolutely correct when you say the evidence of this survey is that without some new stimulation, the employment of disabled people is unlikely to increase significantly.

What you are saying really is that there has to be some program, whether it is my bill, S. 777, or what it is, there has to be some way of opening that door significantly more than we now have. We cannot continue along the present path and think that our problems are going to be solved. Am I misreading what you are saying?

Mr. TAYLOR. No, you have summarized my views very precisely, Senator.

Senator SIMON. I thank you for that generous comment, in addition to what you had to say.

Then, Mr. Russell, as you were talking about people, I thought of one person, I will call her Laura Smith. Smith is really not her last name. She is about 26 years old, maybe 27, she is mentally retarded but she is very pleasant, gets along with people well. Her parents are now both in poor health. One of these days her parents are going to die. Laura Smith is going to probably end up being institutionalized.

If we had a program like this, where we could give Laura Smith a job and give her a chance to contribute in a meaningful way, she could contribute, she would feel better about herself, and the taxpayers would be better off not having to provide custodial help. She might need some minimal kind of assistance in the way of helping her, but what we are doing is confining—and I am not just picking on one person but using her as a symbol—what we are doing is really sending everybody who has a disability, who has not had the good fortune that you and I have had, we are assigning them to the back of the bus in our society.

Again, I guess this is one of these obvious questions, but your strong feeling is we do not need to treat people with disabilities this way, that we will do much better if we have legislation along these lines. Am I reading you correctly.

Mr. RUSSELL. Yes, Senator, I think you are reading my mind correctly. For many, many years, we have espoused the byword and the creed that disability does not mean inability, yet time and time again, in spite of the fact all records show that people with disabilities placed in the right job can do that job as well as so-called "normal" individuals. In spite of that, we see that two-thirds of our people are unemployed and I do not know how much I can say this and how loudly I can say it and how many people I can say it to, but we need opportunity, training and education for our people with disabilities.

I think Senator Weicker deserves so much credit for having the lead in espousing education of children and for people with disabilities, and we need more of this and we can see advances being made, but obviously we have not yet done enough, and this is why we so strongly support and commend the members of this Committee and the members of the Senate for doing the kinds of things that I think have to be done if we are going to reduce this unbelievable dastardly rate of unemployment among people with disabilities.

Senator SIMON. I could not agree with you more. I also agree with you, before I turn it over to my colleague, about the great contribution Senator Weicker has made. He is a giant, not because of his size, he is a little bigger than the rest of us, but he is a giant because of what he has done in the way of helping people who really need help in our society. I am proud to be in the same body with him.

Senator Weicker?

Senator WEICKER. Thank you. Harold and Humphrey, it is good to see you again. I have no questions. I think it was well expressed both by the witnesses and by the Chairman.

Thank you.

Senator SIMON. Thank you both very, very much.

Our final panel includes Bob Callaway, of NewsBank, Inc., New Canaan, Connecticut; Elizabeth Anderson, of Baltimore, Maryland; Susan Suter, the Director, Department of Rehabilitation Services, Springfield, Illinois; and Nina McCoy, Director of Independent Living Center, Indianapolis, Indiana.

We are very pleased to have all of you here.

Senator WEICKER. Mr. Chairman, before the witnesses testify, I want to give a special welcome to Bob Callaway and Angie. I want to welcome Angie here also. I just want welcome the whole panel, and to indicate to you, that I have to be present at a candle lighting ceremony in the Rotunda commemorating the holocaust and I did not want any of the witnesses to feel that I was not interested in their testimony. I am. What I do not hear, I will read. Again, I thank you all for being here and giving your own personal testimony.

Senator SIMON. I join in welcoming all and I have to add that we do have a distinguished citizen of Illinois here among the witnesses. We are pleased to have all of you, whether you happen to be from Connecticut or Illinois or wherever you are from. We are grateful to have you here.

Mr. Callaway?

STATEMENTS OF ROBERT G. CALLAWAY, VICE PRESIDENT OF ADMINISTRATION, NEWSBANK, INC., NEW CANAAN, CT, ACCOMPANIED BY ANDREA LINDMARK, NORWALK, CT; ELIZABETH ANDERSON, BALTIMORE, MD; SUSAN SUTER, DIRECTOR, DEPARTMENT OF REHABILITATION SERVICES, SPRINGFIELD, IL; AND NINA McCOY, DIRECTOR, INDEPENDENT LIVING CENTER, INDIANAPOLIS, IN

Mr. CALLAWAY. I am Robert G. Callaway, Vice President of Administration, NewsBank, Inc., in New Canaan, Connecticut. NewsBank is a publisher of reference information sold to libraries. This published reference information ranges from current events information extracted from over 600 daily American newspapers to U.N. and U.S. government documents which are indexed and published in microform.

NewsBank became involved employing handicapped people after an article appeared in the Stamford, Connecticut Advocate describing people from the STAR Workshop in Norwalk and the Association of Retarded Individuals (ARI) in Stamford, Connecticut, employing people in, among other jobs, as data entry typists.

NewsBank at the time happened to be looking for data entry typists, so we contacted both organizations. NewsBank now has people from both organizations actively employed for over a year as data entry typists and in other editorial support positions.

A little background about our employment area. Fairfield County, Connecticut, the employment situation is very tight there. There is less than a 4 percent unemployment in that area. The cost of living is very high. Therefore, we have a situation where it has been very difficult to hire people in primarily the hourly positions.

STAR and ARI have been excellent solutions to this problem. The handicapped people from these rehab agencies are happy being actively employed. While we have elevated, promoted the tasks of several of these people, they are satisfied with whatever tasks we ask them to perform daily. Their attendance has been excellent and they are willing and able to subscribe to productivity standards.

STAR and ARI differ in their programs. While both programs train their people, ARI trains their people to the point where they can operate independently and they can become in fact regular employees of the company. People coming from the STAR Workshop may require supervision for an extended period of time. They are trained by their supervisors, the supervisors supervise their activities and take responsibility for their productivity. The management at NewsBank works with the STAR people only through the STAR supervisors.

These handicapped people have been integrated into the company life at NewsBank with a minimum of management concern. Other NewsBank employees have adjusted to them and made allowances for their behavior. Let me give you an example. One person who operates a microcomputer for us has a heightened audio sensitivity, making him respond inordinately to vibrations of any kind. The STAR supervisor there has been critical to the supervision of this person in order to keep things like telephone bells, soda machines, anything like that from becoming distractions which might affect not only this person but people around him. As a result, with this type of supervision the STAR people have been able to consistently meet production standards.

In conclusion, our experience employing handicapped individuals has been successful. NewsBank's relationship with the rehab agencies is now over a year old. STAR and other rehab agencies have the organization and they have the support system to create a partnership with companies like NewsBank that work. We intend to continue working with them.

Thank you.

With me today is Angie Lindmark, who is from Westport, Connecticut. She is in a supportive work program for STAR Workshop. She works at the Trudy Corporation in Norwalk, Connecticut.

Thank you.

Senator HARKIN. Thank you very much, Mr. Callaway. I am sorry I had to leave for a minute to go down to another hearing for a while.

Senator WEICKER. Angie, do you have something that you would like to say to the Committee?

Ms. LINDMARK. Okay.

Senator WEICKER. Can we just put the microphone up to Angie, there?

Ms. LINDMARK. I work with teddy bears.

Mr. CALLAWAY. Would you like to tell them what you do?

Ms. LINDMARK. I do all the bears. I do trimming, and I dress the bears.

Senator WEICKER. The Trudy Company has toy bears?

Ms. LINDMARK. We have toy bears.

Senator WEICKER. And you dress the bears?

Ms. LINDMARK. I dress the bears, yes. I do trimming.

Senator WEICKER. And what is the trimming, Angie?

Ms. LINDMARK. I do the dresses.

Mr. CALLAWAY. You do well.

Ms. LINDMARK. I do well.

Senator WEICKER. I do not doubt that. And then, Angie, do you put the bears in bags?

Ms. LINDMARK. Yes, in the bags.

Senator WEICKER. And then what happens? Do the bags get shipped?

Ms. LINDMARK. The bears go in the bags; all the toys are in bags, in the box. And I did it.

Senator WEICKER. And Angie, what do you get paid? Do they pay you?

Ms. LINDMARK. Yes, they pay us—this many pennies—a lot of money.

Senator WEICKER. And what do you do with that money, Angie?

Ms. LINDMARK. I bought a new pocketbook and a beautiful dress. I got a new TV, new table, record player, and new table. That is it.

Senator WEICKER. Angie, where do you live?

Ms. LINDMARK. I live in Westport, Connecticut.

Senator **Weicker**. Do you live in your own home?

Ms. **Lindmark**. Group home.

Senator **Weicker**. In a group home. And you have your own room?

Ms. **Lindmark**. Yes. I have a roommate, but he is going to Florida for a vacation.

Senator **Simon**. Angie, may I ask, do you like your work?

Ms. **Lindmark**. I like my work. I like it down there. I work hard down there. I am a good worker.

Senator **Weicker**. Angie, did you ever live in an institution?

Ms. **Lindmark**. I lived at Southport Women's School.

Senator **Weicker**. Did you like that?

Ms. **Lindmark**. Yes, I liked it.

Senator **Weicker**. Do you like your home better?

Ms. **Lindmark**. Yes, in Westport, Connecticut.

Senator **Weicker**. Angie, thank you very much for coming and telling us about your work. And I am very proud of you.

Ms. **Lindmark**. Thank you.

Senator **Simon**. We are all proud of you.

Senator **Harkin**. I want to echo that, too. We are all proud of you, Angie. You are an example for many, many people in this country, a good example.

Ms. **Lindmark**. Thank you very much.

Senator **Harkin**. Thank you very much, Angie.

Our next witness is Elizabeth Anderson.

Ms. **Anderson**. Yes, I am Elizabeth Anderson. I am past President of the National Rehabilitation Association and I have just been named to the National Planning Council of the President's Committee on Employment of the Handicapped.

I am a consultant at Howard University with Dr. Sylvia Walker, who is Director of the Center for the Study of Handicapped Children and Youth. She regrets she could not be with you today.

I would like to put the remarks I have to say within the construct of the black experience in rehabilitation and the black experience in terms of being disabled.

Senator Simon, I must depart a moment from my presentation to say that I was in your State, Illinois, in 1979, at the very first celebration of National Rehabilitation Month and at that time I was President of the National Rehabilitation Association. I am pleased that your State had the honor of celebrating that great occasion.

During the course of my total experience in rehabilitation, it has been a matter of black disabled people trying to get rehabilitation, which is the first step in trying to get a job. It is the greatest rehabilitation system in the world.

South Carolina is our number one State in the State-Federal program, both in cost effectiveness and the number of people that are rehabilitated in a single year. That is great!

In 1974, yes, we do things for ourselves, too, we had the very first conference nationally about black people and rehabilitation at Tuskeegee Institute in Tuskeegee, Alabama. We found that 6 percent of the graduate students in rehabilitation programs were black. That has changed somewhat.

In 1977, we had to kick our way into participation in the White House Conference on Handicapped people in the United States of

America. Black people were totally excluded nationwide from the program planning for this great program, the first that ever occurred, and we were excluded.

In terms of the National Rehabilitation Association, almost overall, with rare exceptions, black people were excluded until 1969.

Baby Doe in Indiana, is part of the construct. Baby Doe was born with birth defects. She had accepting foster parents in 1982. By judgment of the court, she was allowed to starve to death despite the accepting foster parents. More recently, another baby with birth defects, in Long Island, where I am from, was allowed a similar fate.

I was in the Soviet Union a couple of years ago; I was invited to present a program on our rehabilitation system in America. I was struck by the fact that they would not let us see whatever it was they were doing in rehabilitation. I was struck by the fact that there were no curbcuts, there was nothing that said there was accessibility for disabled persons. I did not see one person with birth defects, not one blind person, not one deaf person.

Not too long after Baby Doe, there was a governor in Colorado named Lamb; he said perhaps it would be a good idea for old people to give up their lives so that they would not be a burden on society. He thought the elderly used too many resources.

These are constructs and supports in our society that are failing. When this diminution takes place, it takes place for all of us. There was a time in Harlem in the 1930s when drugs were rampant in the streets; the body politic and the people of Harlem demanded that they take drugs out of Harlem. The response was, all right, give it to Harlem but do not give it to our kids in Westchester, or Long Island, or Connecticut. Now, drugs are everywhere.

Without the Civil Rights Act of 1964, there could not have been a Rehabilitation Act of 1973, and its amendments, nor the Education For All Handicapped Children Act. But still in 1987, 82 percent of black disabled people are unemployed! Of the small 18 percent that are employed, 65 percent earn less than $4,000 a year! This is unacceptable!

Rehabilitation is the best system, the very best system there is. No one on this planet matches our system of rehabilitation. Yet we tolerate this unacceptable situation. It must be changed!

Now, how do we change it? We change it by implementing the great laws of our Congress and the people of the United States.

In the State of New York, where I am from, Ross & Biggi, in 1986, selected a group of white and non-white clients in the State system for analysis and study. They found that "failure to cooperate" was the most predominant reason stated for closure of non-white clients, while "refused services" was the primary reason for closure of white clients.

In addition, this study showed that placement rates for 26 closures for white clients increased by 2 percent, while the placement rate for non-white clients decreased by 18 percent in the Empire State! We have to pay attention to that. They found that the rehabilitation rates for white clients increased by 4 percent, while those for non-white clients decreased by 4.5 percent. They found that there was a high tendency for white clients' cases to be closed, when placed in jobs, at higher than the minimum wage. Non-white clients' cases were closed nonrehabilitated, no jobs! These findings support similar estimates in the Atkins & Wright study. Considering the benefits of rehabilitation, black clients fared disproprotionately worse than white clients in the system.

In terms of what we have done about it Howard University, is the only historically black university that has received grants to study disabled black Americans, Howard University has developed some models for placement and training of black people in rehabilitation.

In one of the models developed, five homeless disabled black ladies were placed in the counseling and training program that was developed at Howard University; all five, on their own, were able to secure employment. I present the book, "Equal to the Challenge," published in 1986 by Howard University. This is the first effort of its kind in the field of rehabilitation. It is a prototype.

In addition, they have developed a video at Howard University to assist in interviewing black people who are disabled for job placement. There is a difference. There seems to be a difference in language, the type of language, the content of language for interviews, the behavioral posture of the body in interviewing for a job that is different. We have to utilize this information to more effectively place people in jobs.

In Long Island, Helen Kaplan, was infuriated by the fact that persons who were mentally disabled were not able to get jobs, The mentally retarded, as they were called, because they had an IQ of less than 60 were unacceptable in some rehabilitation programs- She set out to prove them wrong.

She opened up a workshop in Hempstead, Long Island, for mentally retarded persons, with IQs of 20 to 50. It was a success. We have to do more.

Your bill, which is excellent, should do all the things that it is designed to do, and I think it will. But, we see that there is need for an extra step, an extra effort that has to be made to include disabled black people in the job market in this country. We cannot continue to drain our resources when there are people who are ready and willing to work, trainable, and who should be a part of our great country in every aspect.

Now, the greatest barrier for all disabled people who want to work is, No. 1 transportation. We still cannot get on buses, on trains to get where we have to go to get work. We cannot get into buildings because buildings are not accessible. Many of them are public buildings, State, local, Federal; also churches, we cannot get in due to architectural barriers. We have to do something to change that.

We have to develop social consciousness and sensitivity so that we do not become uncomfortable when a black person who is disabled, or any disabled person, comes into the room. We should not increase our discomfort level.

They are just as good, many are 2,000 percent better. People who are apparently temporarily able-bodied could not accept nor achieve nor succeed at the challenge faced every day by a person with severe disability.

To get back to the macro picture, in terms of prevalence, incidence, and severity of disability, black people have more than anybody else. Among the total body of blind, disabled persons in the United States, the highest number of people in that group are black people, because of the incidence and prevalence of diabetes.

I will conclude my report by saying that I want your bill to do everything that it is designed to do, but we must be aware of the extra steps that are necessary to make it succeed where it is most needed, the 82 percent unemployed disabled Black Americans.

Thank you.

[Material supplied for the record follows:]

Communication and Networking: Vital Links in the Rehabilitation and Employment of Disabled Black Americans

Mrs. Elizabeth H. Anderson
Past President
National Rehabilitation Association

Paper Presented at the National Conference--Employment Successes, Problems, and Needs of Disabled Black Americans. Howard University, Washington, D.C., February 11-13, 1987.

Communication and Networking: Vital Links in the Rehabilitation and Employment of Disabled Black Americans

Mrs. Elizabeth H. Anderson
Past President
National Rehabilitation Association

Introduction

Communication is sending and receiving information. It girds human behaviors as well as relationships between individuals and among groups. There are forms, systems, and a process of communication. Communication shapes ideas and defines the individual. Communication is multidimensional, it transforms international, industrial, management, and administrative relationships. It touches every aspect of modern life including education, marketing, science, and medicine. Communication is intrinsic to theology, literature, art, and architecture.

Communication is the essence of all human interaction in the universe, our values and value systems, our courtesy and manners, our child rearing practices and family relationships. Communication engenders our ability to reason, to think and to learn.

World behaviors and behavioral responses have been changed, opinions and attitudes formed and altered, by influences of mass media, such as radio, newspapers, periodicals, theatre, and motion pictures, and by what has been called imperious communication: television. Its influence, importance, and impact cannot be diminished nor denied.

In rehabilitation, we have in recent years begun to command the attention of the world with such events as The Year of the Disabled, National Rehabilitation Month, and National Employ the Handicapped Week.

Mass media projection of fund raisers for various disabilities have for the most part been successful. However, our communication efforts have not yet reached the point that we can avoid explaining to the average person, who we are and what we do when we say we work in rehabilitation.

The Challenge

Rather than focusing on a large number of barriers to communication as they relate to the rehabilitation of disabled black Americans, let me mention a few. Most Americans don't hear the message that based upon prevalence, incidence and severity, black people and particularly, black women, have proportionately more disability than the general population. Bowe (1983) found that disabled black people are less educated and earn less than non-disabled black people. The real tragedy is that 82% of black disabled persons are unemployed. When employed, 65% of this population earn less than $4,000 per year!

Walker, et al (1986), found that the primary source of income for this group is public assistance. One of the ways to meet this challenge is advocacy and self-advocacy for education, job training, and placement. The public education system and the Federal-State vocational rehabilitation program, which utilizes public and private vendors, are primary providers.

Ross and Biggi (1986) selected a group of white and non-white clients in the New York State Office of Vocational Rehabilitation for analysis and study. They found that "failure to cooperate" was the most predominant reason stated for closure of non-white clients, while "refused services" was the primary reason for closure of white clients. In addition, this study showed that placement rates for 26 closures for white clients increased by 2%, while the placement rate for non-white clients decreased by 18%! Further, they found that rehabilitation rates for white clients increased by 4%, while those for non-white clients decreased by 4.5%. They found that there was a higher tendency for white clients cases to be closed, when placed in jobs, at higher than the minimum wage, while non-white clients cases were closed non-rehabilitated (Ross and Biggi 1986).

These findings support the Atkins and Wright (1980) view that considering the benefits of rehabilitation, black clients fared disproportionately worse than white clients in this system. Clearly, new directions and approaches are needed to facilitate the access of black persons to this system.

Effective Communication Strategies

Our federal rehabilitation program is the largest, if not the best in the universe. It is funded at over one billion dollars a year. Officials at the helm of the rehabilitation system affirm their intent to make services accessible to black disabled persons and historically black colleges and universities. However, large gaps in services persist.

We need more resources such as the Information Center for Handicapped Individuals in Washington, D.C., which provides information and referral services, a client assistance program to follow up on referrals to ensure effective and timely service delivery, as well as other services. With supports such as these, black disabled individuals can be equipped with assertiveness and self-actualization (Galiber 1986).

Access to these services and information systems implies the utilization of media resources for outreach. The Howard University Center for the Study of Handicapped Children and Youth produced a videotape training tool, "Disabled But Not Unable: Dispelling Myths About Disability" which has been favorably received. That Center also publishes a newsletter and utilizes TV Channel 32 and the radio for outreach.

Centers for Independent Living are utilized for referral and such centers are excellent avenues for communication of the accomplishments and needs of the disabled. Staffing of these centers at the outset should represent the entire community of the disabled, including black disabled persons to ensure access to services and to dissuade subtle or overt rejection behaviors.

Physical access to buildings, parking lots, and transportation systems remain a high priorty item for persons who are disabled. These needs must be communicated to the appropriate agencies so that action to increase accessibility may be taken. Advocacy organizations primarily of, by, and for persons who are disabled should make every effort to include black persons.

In the immediate social contact area for black disabled persons are family, friends and the church. The church is a focus for the community. Wells and Banner (1986) found that there is a significant role for outreach, support and advocacy to be played by the black church. They found that by networking through this key resource, disabled persons and service providers could protect and ensure rights for the disabled. This role for the church was enunciated at a conference for resource exchange in collaboration with the United Methodist Churches of Rome and Cedartown Georgia, and the Howard University Model to Improve Rehabilitation Services to Minority Populations. This role of the church is to cooperate with and support social and vocational rehabilitation agencies. Volunteers also have meaningful roles in this support system.

While the usual job placement opportunities are being developed, the role of black disabled individuals as entrepreneurs, owners and operators of small businesses should not be overlooked. Local chambers of commerce, Junior Achievement, trade associations, labor unions, and professional organizations should provide important linkages. Projects with industry should include advocacy for hiring black disabled persons. Corporate and company responsibility should be assumed to assure job success. Nationally known fast food organizations have openings at many levels of operations; they should be encouraged to hire black disabled persons.

The value of developing a substantial number of self-advocates among the black disabled population cannot be over emphasized. There is a vital need to encourage larger numbers of blacks with handicapping conditions to become active in advocacy organizations at both the local and national levels. Such individuals should become active in disability rights groups as well as in traditional civil rights groups such as the NAACP and community organizations such as the Urban League.

Primary health care providers are a growing job resource. Through their rehabilitation counselors, occupational and physical therapists, social workers, and others, clients could be provided with disabled role models, and positive examples of the benefit of work as a desirable objective. In-house workshops should not be the limit for disabled persons. Many could and should consider black disabled persons for staff positions by creating on-the-job training opportunities. Suppliers of health care facilities should be oriented to provide job opportunities for disabled applicants.

Conferences, workshops, and seminars are excellent vehicles for the dissemination of information. Since 1985, Career Exploration Conferences held at Howard University for disabled persons have attracted t least thirty-six employers and over 200 attendees at each meeting. Such conferences are important first steps to open doors to black disabled persons seeking employment, as well as for employers seeking a resource for employee recruitment.

Each rehabilitation counselor (as well as other service providers) should view his/herself as a mechanism for the communication for ideas and policies which facilitate the success of all disabled Americans (including blacks and other non-whites). Professionals should view the role of advocacy as a vital component of their job responsibility.

Personal responsibility with appropriate supports, should be assumed to obtain successful employment and job maintenance. This would include periodic self-assessment, as well as the traditional evaluation by supervisors. Setting goals with timetables should reflect reality-based planning with possibilities for adjustments and revisions leading to higher level positions. Additionally, opportunities for in-service training should be part of in-house information systems. However, one should not diminish the importance of the company grapevine as an essential communication resource.

Rehabilitation and job placement for disabled persons is the single most successful investment that is made with the expenditure of federal dollars in the human services system. Earnings and jobs produce taxpayers and restore human dignity.

> "To whom shall I speak today?
> People are greedy
> Everyone seizes the possessions of his neighbor.
> To whom shall I speak today?
> Gentleness of spirit has perished.
> All the people are impudent.
> To whom shall I speak today?
> One laughs at crimes that before
> Would have enraged the righteous.
> To whom shall I speak today?
> There are no just men.
> The earth has been given over to evil doers."

This Egyptian poem, written when the Old Kingdom was in turmoil, has the title, "The Struggle with His Soul of One Who is Tired of Life," and is quoted in Davidson, et al. (1982). It gives food for thought in a perilous world with very delicate balances designed to avoid and avert war.

When considering societal responsibility for the rehabilitation of disabled persons, some people see problems as challenges and rise to meet them. Others see barriers as opportunities for creative innovation. Society in its diversity and complexity provides no diminution nor simplification for either. Societal responsibility for the rehabilitation of disabled persons remain in place mainly because of the faith, perseverance, and persistance of those in both groups. We must endure. We must continue.

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SECTION I

Past and Present Implications for Rehabilitation

1 • Rehabilitation for the Nonwhite Disabled: A Formidable Challenge

ELIZABETH H. ANDERSON
National Rehabilitation Association

Abstract

This article states that blacks are overrepresented among the handicapped in America. It addresses the effects of federal cutbacks in social security and their impact on handicapped minorities. It compares some of the negative attitudes toward the handicapped in this country with those in Russia. The article also presents a systematic approach for maintaining federal and state funding for the nonwhite community during this period of fiscal restraint. It calls for intense advocacy by those who work with, support, and represent the minority handicapped in America in an effort to abate the fiscal cutbacks in government.

Based upon prevalence, incidence, and severity, black Americans are clearly in the forefront of disabled persons in America. Causation is varied and complex: birth defects, disease, trauma, war, substance abuse, mental illness, neurological and circulatory conditions.

The arcane program of peremptory disallowance of social security disability benefits without a hearing has created havoc, destruction, and the ultimate . . . death, among many disabled persons. As advocates, our role must be to ensure the reinstatement of disabled persons so cruelly, wantonly, and senselessly assailed.

Let's look back to April 1982. In Indiana, Baby Doe was born with Down's Syndrome and digestive tract defects. Her natural parents rejected her. Although there were loving, accepting adoptive parents waiting for her in their warm homes, a judge, acting upon the plea of the natural parents, ruled that it was permissible, legally, to allow Baby Doe to starve to death.

By contrast, in Indiana, a rock group was performing and as part of their act, one of the performers bit off the head of a bat. The performer was arrested for cruelty to animals.

Since the first Baby Doe, there have been several cases with the same outcome. Where was the hue and cry for the rights of the born?

In the absence of such advocacy, the Surgeon-General of the United States, Dr. C. Everett Koop, played a major role in attempting to deal with the problem. He stated, "Each newborn infant, perfect or deformed, is a human being with unique preciousness because he or she was created in the image of God." Rules promulgated by the U.S. Department of Health and Human Services (HHS) are designed to protect these infants. The Department is being sued by the American Hospital Association. An appeal on a negative decision by the United States District Court invalidating the HHS rules is in litigation.

Earlier this year, 1984, the Governor of Colorado implied that the elderly were using too many resources and should oblige the rest of society by giving up their lives. You can make your own inferences.

Last year, I was in the USSR to attend a rehabilitation seminar. In Moscow, a city of six million, I was struck by the absence of blind people, the absence of accessibility, the absence of those with birth defects, the absence of a person using a cane or crutch, the absence of the elderly. The same was true in Leningrad, a city of four to five million people. I was not given information about these absences, although I was in the USSR for two weeks. I got the clear impression that the USSR is a society where you produce or you are in trouble. Consider, there is no accessibility: not in buildings, the streets, airports, airplanes, or other public conveyances.

In 1977, the National Urban League and the National Association of Nonwhite Rehabilitation Workers, in cooperation with the White House Conference on Handicapped Individuals, developed a national program designed to examine rehabilitation in nonwhite communities. The program was funded by a federal grant. It is significant that seven years later we must continue to address these concerns.

Within the largest and most successful rehabilitation program in the world, the federal-state program in the United States of America, we see attempts each year to reduce funding and appropriations required to provide rehabilitation services for the disabled. If it were not for the National Rehabilitation Association, its members and friends, program and staff cuts already in progress would have been much more severe. I call your attention to the attached tables showing the administration's fiscal year 1985 budget as compared to the House and Senate recommendations. These figures reflect the efforts on the part of the Congress to appropriate a larger sum of money to the disabled community than that budgeted by the administration (See Appendix).

In order to continue this program, *we must be funded.* That is the bottom line. Your advocacy, your letters and phone calls to your Senators and Congressmen are essential to the continuation of this program. One of the battle cries of the new right is "cut social programs."

Keep in mind that most disabled persons who receive rehabilitation services do become wage earners and taxpayers. For example, in South Carolina, the number one federal-state program in the country and also the number one chapter in the National Rehabilitation Association, there were 8,000 successfully rehabilitated clients in 1982. These 8,000 successes increased their annual rate of earnings from $17.2 million to $55.2 million, a net increase of 66%. Rehabilitation costs are usually a one time expenditure for each client. Among this successful group of 8,000, 50% had mental disabilities. Other disabilities were: digestive tract disorders; hearing impairments; heart and circulatory conditions; allergy and endocrine disorders; visual impairments; epilepsy and other neurological disorders; respiratory diseases; absence of limbs; cancer; speech impairments; blood disorders; and other conditions.

With our active participation to assure continued funding for federal-state programs at minimal levels, we can meet the fiscal demands for rehabilitation needs in the nonwhite community as follows:

- Staff training, to ensure job access to rehabilitation positions at both graduate and undergraduate levels, must be pursued. Effective recruitment methods and programs must be developed within the nonwhite community.
- Outreach programs for disabled persons in nonwhite communities must be established at every point of contact e.g., schools, churches, doctors, hospitals and clinics, unions, worker's compensation, welfare, social security disability, and community organizations. Effective referrals to rehabilitation agencies must be made with adequate follow-up.
- Facilities and facility development must be initiated in nonwhite communities.
- Advocacy for the enforcement of the

Rehabilitation Act of 1973 and its amendments must be more persistent, tenacious, creative, innovative, and effective. Information and information systems as well as stimulation must be provided and utilized to prevent discrimination against disabled persons and to provide public acceptance for these laws. Every available means of communication should be utilized including the media.

- Disabled nonwhite persons must be included at every level in organizations of disabled persons as well as local, state, and federal advisory councils and instrumentalities.
- Immediate steps must be taken to include the nonwhite community in grants programs throughout the rehabilitation community in order to encourage research and innovation.
- Projects with industry must be a *sine qua non* to ensure job opportunities for persons who are disabled in nonwhite communities.
- Accessibility in schools at every level to facilitate mainstreaming must continue.
- Accessibility to vote and voter education are essential for every eligible disabled voter.
- National Rehabilitation Month, September, must be proclaimed as a national priority.

In closing, here is an illustration of "What Went Wrong?" It is a story about four people: Everybody, Somebody, Anybody, and Nobody.

There was an important job to be done and Everybody was sure that Somebody would do it. Somebody got angry because it was Everybody's job. Anybody could have done it, but Nobody did it. Everybody thought that Somebody would do it. But Nobody asked Anybody. It ended up that the job wasn't done, and everybody blamed Everybody when actually Nobody asked Anybody.

In the book of Ecclesiastes, it is said that there is a time for all things. LET US BEGIN!!!

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Senator **Harkin**. Mrs. Anderson, thank you very much. You are very good. That was a very powerful statement.

Again, I think before we get on to questions, I would ask Senator Simon if he would introduce our next witness.

Senator **Simon**. First of all, I want to join in saying, Mrs. Anderson, you were great. What an eloquent statement.

Susan Suter heads our Department of Rehabilitation Services in Illinois and we are very proud of her and we are pleased to have her as a witness here.

Senator **Harkin**. Susan, we are delighted to have you and please proceed.

Ms. **Suter**. Thank you.

Senator Simon, I would like to thank you and Senator Harkin for the opportunity to speak before your Committee this morning. And, Senator, I would like to commend you on your book which addresses unemployment and its effects on the American economy. Not since Studs Turkel has anyone examined unemployment through the eyes of the unemployed.

It is important to note that you have taken Mr. Turkel's concept and expanded it to include people with disabilities as those who are among the group identified as "unemployed but employable." Your interview with a Springfield, Illinois, man who is blind and out of work struck home with me. It was a reminder that unemployment is not someone else's problem, but truly one that exists in our own neighborhoods.

You have examined the problem of unemployment. But as one of America's 36 million people with disabilities, I must take exception with your finding that only 10 million of our Nation's people are unemployed.

A Lou Harris poll released last year found that two-thirds of people with disabilities who are of working age are unemployed. Although a majority of them wanted to work, they lacked sufficient education or training. When people with disabilities are out of work and that is taken into account, the "10 million unemployed" figure that your findings indicate is more than doubled, to include at least 22 million Americans.

The future remains bleak for many people with disabilities and their families. Most of them are destined to remain living in poverty and earning wages of less than $8,500 a year.

As welfare reform is being debated throughout the Nation, people with disabilities are often mistakenly assumed to be America's "takers," instead of "contributors," as many of them would rather be.

I can assure you, from a rehabilitation agency, employment is the number one priority among people with disabilities in our Nation's rehabilitation agencies.

With these remarks in mind, I have examined S. 777 and have found it to be a means of providing opportunities for employment for people with disabilities. Although this bill would not replace previous rehabilitation legislation, it could provide supplementary support to the Rehabilitation Act. This support would not be without a major commitment in spending. Therefore, if Congress decides to pursue this legislation, I suggest these points be kept in mind:

First and foremost, this bill must not be a "quick fix" or a short-term solution that fails to address the long-range problem of unemployment in America. Unemployment's causes are too complex and too complicated to be merely solved by an act of Congress.

This bill must provide relevant job training and applicable skills for the jobs of tomorrow, as well as for the jobs of today. And it must be targeted toward those people who are most likely to benefit from this "helping hand" so that they will go on to improve the course of their lives, independent of public assistance.

This bill has many similarities to the New Deal public works programs of the 1930s. It would be helpful to reexamine the procedures and policies followed by those programs to establish practical guidelines for effective implementation of the bill.

During the past two years, Illinois has implemented a similar work program under the name of "Build Illinois." This program has successfully put people to work and improved the economic conditions of communities hard hit by the recession in agriculture, while it has improved our State's infrastructure, public roads and parks.

In fact, some of Illinois' parks that were originally constructed during the 1930s are now being modernized and rehabilitated through this public works program. Build Illinois is supplying the funding and manpower, much as your proposed bill could do on a nationwide basis. The projects of the 1930s and Build Illinois have taught us that work programs can be effective.

We must also insure that the drive and self-initiative of the individuals who are being employed by these projects is maintained. By its very name, the Guaranteed Job Opportunity Act implied that this is an "opportunity," only a means to an end, not an end in itself. The short-term opportunities funded in this bill should serve as a means of motivating individuals to be able to become independent in our society.

As I stated earlier, unemployment among people with disabilities is unacceptably high. We offer these additional comments and suggestions on your proposed bill as a means of lowering the jobless rate among Americans who are disabled:

Section 5 states that a Private Industry Council located in the same delivery area of what the bill defines as an "eligible area" may petition to serve as that district's executive council.

Care should be given to insure that this is done whenever possible to avoid unnecessary redundancy in government and duplication of similar services. We also urge that people with disabilities be included on these councils.

We question, as you heard this morning, the omission of heavily populated communities from "eligible areas" for projects funded in this bill. By allowing only those areas with a population of 300,000 individuals or less to participate (unless this requirement is waived by the Secretary of Labor), the effectiveness of this bill could be significantly reduced in heavily industrialized States such as Illinois.

Although the concept of "double-dipping" off the public payroll should be discouraged, the prohibition against holding a secondary job for more than 16 hours a week should be examined.

A calculation of the minimum wages earned under this program indicate that if an individual is paid at the prevailing Federal minimum wage rate of $3.35 an hour and works 32 hours, he or she will be paid only $5,574 a year. This is just not enough to live on, which brings me to the next point.

Once again, the issue of "disincentives to work" that are often a part of the Social Security system must be addressed by this bill. Are wages that are as low as $5,000 annually or only 10 percent above an individual's current Social Security or welfare payment a realistic incentive to go to work? Individuals may choose to remain unemployed rather than face the requirements of this bill.

Also, once the work project has been completed, are there provisions for Social Security benefits to be reinstated to individuals who still need them, particularly individuals with disabilities?

Under "testing requirements" and English speaking proficiency, we concur with the bill's provision for waiver of these requirements for people with disabilities who, due to their impairments, may be unable to be tested by ordinary means.

We are not suggesting that people with disabilities should be guaranteed placement without being required to satisfactorily demonstrate their ability to perform the duties of the job. No one should be exempt from demonstrating their work skills or their employability.

We also concur with the provisions for job clubs and supportive services defined as those "which may include transportation, health care, special services and materials" for people with disabilities. These services will allow more people with disabilities to participate in the program. Too often we try to "fix" the person with the disability, and I think it is called blaming the victim, when the truth is it is not the disability but other barriers in society, such as transportation and housing, that prevent employment.

We take exception to section 6 which limits eligibility for participation in this program to not more than two persons who reside in any one household.

As the trend towards de-institutionalization continues, more and more people with disabilities are living in neighborhood half-way houses or group homes. This provision would prevent residents of these homes from participating in the program.

Although your bill pays substantial attention to job security of persons currently employed and to guaranteeing that prevailing wages be paid to workers, there is no specific mention of people with disabilities as a group which will be protected under the terms of this bill.

Your bill guarantees non-discrimination toward people who are disabled (as defined in Section 504 of the Rehabilitation Act), but as long as 12 million people with disabilities of working age remain unemployed, we urge you to include specific language that list people with disabilities as among those who could benefit from work opportunities provided by this bill.

Mr. Simon, we share your dream for America and for America's people, and we too wish to see competitiveness and productivity restored to the workplace. And we want to see America use, as you suggested earlier, a largely untapped resource and that is people with disabilities.

I would like to separate from my remarks just for a moment to address Senator Harkin's question about employing people with disabilities. I cannot say it any better than Angie has said it here this morning: We need to change attitudes and we need to change expectations about people with disabilities becoming employed.

We in Illinois have a supported employment project and I think nothing exemplifies it better than this: In our project we have 348 people with severe disabilities and the project has been going for two years. They are earning $1.7 million in salaries. They are paying $100,000 in taxes. And I think almost more importantly, we have found that after they have been on the job, when they start the job we have job coaches and professionals that provide those support services that people need to stay on the job.

Over a two-year period, we have seen the need for the job coaches and the professional services decline as co-workers are providing some of the support and they are glad to do it, and I think that is truly an indication of integration in society of people with disabilities and community involvement, and I think this bill will help us get to that point.

Thank you.

[The prepared statement of Ms. Suter follows:]

Director Suter's Testimony before
Senator Paul Simon's Hearing on
Senate Bill 777 (The Guaranteed Jobs Opportunity Act)
April 27, 1987

I am Sue Suter, Director of the Illinois Department of Rehabilitation Services. Before I begin, I would like to thank you, Senator, and your Committee, for this opportunity to speak on behalf of people with disabilities.

Senator Simon, I would like to commend you on your book which addresses unemployment and its effect on the American economy.

Not since Studs Turkel has anyone examined unemployment through the eyes of the unemployed.

It is important to note that you have taken Mr. Turkel's concept and expanded it to include people with disabilities as those who are among the group identified as "unemployed but employable." Your interview with a Springfield, Illinois, man who is blind and out of work struck home with me. It was a reminder that unemployment is not someone else's problem, but truly one that exists in our own neighborhoods.

You have examined the problems of unemployment. But as one of America's 36 million people with disabilities, I must take exception with your finding that only 10 million of our nation's people are unemployed.

A Lou Harris poll released last year found that two-thirds of people with disabilities who are of working age are unemployed. Although a majority of them wanted to work, they lacked sufficient education or training. When people with disabilities who are out of work are taken into account, the "10 million unemployed" figure that your findings indicate is more than doubled to include at least 22 million Americans!

The future remains bleak for many people with disabilities and their families. Most of them are destined to remain living in poverty and earning wages of less than $8,500 a year.

As welfare reform is being debated throughout the nation, people with disabilities are often mistakenly assumed to be America's "takers," instead of "contributors," as many of them would rather be.

Mr. Simon, with due respect, I also take exception with the point made in your book that unemployment is not a priority among Americans. I assure you that it is the No. 1 priority among people with disabilities and the agency I represent in Illinois.

With these remarks in mind, I have examined Senate Bill 777 and have found it to be a means of providing opportunities for employment for people with disabilities. Although this bill would not replace previous rehabilitation legislation, it could provide supplementary support to the Rehabilitation Act. This support would not be without a major commitment in spending. Therefore, if Congress decides to pursue this legislation, I suggest these points be kept in mind:

1) First and foremost, this bill must not be a "quick fix," or a short-term solution that fails to address the long-range problem of unemployment in America.

Unemployment's causes are too complex and too complicated to be solved merely by an act of Congress.

This bill must provide relevant job training and applicable skills for the jobs of tomorrow, as well as today's. And it must be targeted toward those people who are most likely to benefit from this "helping hand" so that they will go on to improve the course of their lives, independent of public assistance.

With a hefty price tag of $5 billion for its first year alone, America cannot afford - nor should it guarantee - a "chicken in every pot" for every American out of work, unless he or she can demonstrate a true willingness to return as much to the American economy as has been received. Our escalating federal deficit will not allow otherwise. Persons with disabilities do demonstrate their willingness to work.

2) This bill has many similarities to the New Deal public works programs of the 1930s. It would be helpful to re-examine the procedures and policies followed by these programs to establish practical guidelines for effective implementation of this bill.

During the past two years, Illinois has implemented a similar work program under the name of "Build Illinois." This program has successfully put people to work and improved the economic conditions of communities hard-hit by the recession in agriculture, while it has improved our State's infra-structure, public roads and parks.

In fact, some of Illinois' parks that were originally constructed during the '30s are now, 50 years later, being modernized and rehabilitated through this public work program. Build Illinois is supplying the funding and manpower, much as your proposed bill could do on a nation-wide scale. The projects of the 1930s and Build Illinois have taught us that work programs can be effective. However, a word of caution: the projects provided in this bill are an open invitation to "pork barrel" politics. Careful scrutiny as to the intent and potential outcome of each project must be maintained when deciding where and how the money appropriated for this bill will be spent.

3) We must also insure that the drive and self-initiative of the individuals who are being employed by these projects is maintained.

By its very name, the "Guaranteed Job Opportunity Act" implies that this is an "opportunity" - only a means to an end, not an end in itself.

The short-term work opportunities funded in this bill should serve as a means of motivating individuals to ultimately "go it" on their own.

A "helping hand" (as this bill is intended to be) should never be allowed to become an "armload of handouts" for those who may abuse the system or misconstrue its intent. The pressing need for reform of our nation's welfare system clearly demonstrates that generations can become dependent on government intervention.

As I stated earlier, unemployment among people with disabilities is unacceptably high. We offer these additional comments and suggestions on your proposed bill as a means of lowering the jobless rate among Americans who are disabled:

A) Section 5 states that a Private Industry Council located in the same delivery area of what the bill defines as an "eligible area" may petition to serve as that district's executive council.

Care should be taken to ensure that this is done whenever possible to avoid unnecessary redundancy in government and duplication of similar services. Electing to use the existing Private Industry Council could also save additional administrative expenses and improve delivery of services provided under this bill.

If, however, a district chooses to have both an executive council and a Private Industry Council, the language of this section should clearly define which body would be in charge of that district's work projects. We also urge that people with disabilities be included on these Councils.

B) We question the omission of heavily populated communities from "eligible areas" for projects funded in this bill. By allowing only those areas with a population of 300,000 individuals or less to participate (unless this requirement is waived by the Secretary of Labor), the effectiveness of this bill could be significantly diminished in heavily industrialized states such as Illinois.

C) Although the concept of "double-dipping" off the public payroll should be discouraged, the prohibition against holding a secondary job for more than 16 hours a week should be examined.

A calculation of the minimum wages earned under this program indicate that if an individual is paid at the prevailing federal minimum wage of $3.35 and works 32 hours (the maximum allowed under the terms of this bill), he or she will be paid only $5,574.40 a year. This is just not enough to live on, which brings me to our next point.

(6)

D) Once again, the issue of "disincentives to work" that are often a part of the Social Security system must be addressed by this bill. Are wages that are as low as $5,574 annually or only 10 percent above an individual's current Social Security or welfare payment worth the effort? Individuals may choose to remain unemployed rather than face the requirements of this bill.

Also, once the work project has been completed, are there provisions for Social Security benefits to be reinstated to individuals who still need them? This issue should also be addressed.

E) Under "testing requirements" and English speaking proficiency, we concur with the bill's provision for waiver of these requirements for people with disabilities who, due to their impairments, may be unable to be tested by ordinary means.

We are not suggesting that people with disabilities should be guaranteed placement without being required to satisfactorily demonstrate their ability to perform the duties of the job. No one should be exempt from demonstrating their work skills or their employability.

F) We also concur with the provisions for job clubs and supportive services defined as those "which may include transportation, health care, special services and materials" for people with disabilities. These services will allow more of them to participate in the program.

G) We take exception to Section 6 which limits eligibility for participation in this program to not more than two persons who reside in any one household.

As the trend toward de-institutionalization continues, more and more people with disabilities are living in neighborhood half-way houses or group homes. This provision would prevent residents of these homes from participating in the program.

H) Although your bill pays substantial attention to job security of persons currently employed and to guaranteeing that prevailing wages be paid to workers, there is no specific mention of people with disabilities as a group which will be protected under the terms of this bill.

Your bill guarantees non-discrimination toward people who are disabled (as defined in Section 504 of the Rehabilitation Act); but as long as 12 million people with disabilities of working age remain unemployed, we believe that specific language should list people with disabilities as among those who could benefit from work opportunities provided by this bill.

Mr. Simon, we share your dream for America and our nation's people. We, too, wish to see competitiveness and productivity restored to the work place.

This bill is a monumental attempt to revitalize the American economy and put our nation's people back to work. However, it is not legislation without a heavy investment of tax dollars. We hope that members of your Committee and Congress will give consideration to the concerns we have raised regarding unemployment among people with disabilities when deciding appropriate action on this bill.

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Senator HARKIN. Thank you very much for a very fine statement.

Now we will turn to Nina McCoy, Director of Independent Living Center, Indianapolis, Indiana. Welcome to the Committee and, again, your statement will be made part of the record and please proceed.

Ms. MCCOY. Good morning. I am very pleased to be here this morning representing the Consortium for Citizens with Developmental Disabilities, a coalition of over 60 national consumer, professional, and provider organizations, but more importantly, the millions of Americans represented by these organizations.

I am also here on behalf of United Cerebral Palsy Associations, Inc., which is a national network of community-based providers of services to persons with severe physical disabilities. There are currently 180 affiliates in 45 States across the country concerned with meeting the needs of persons with cerebral palsy and their families.

In recent years, UCP and CCDD have become increasingly active ensuring that integrated employment opportunities exist for all individuals with cerebral palsy and other severe disabilities. We believe this is a realistic objective for all disabled individuals given the proper job training and community support.

As you have heard earlier this morning, the economic picture for disabled individuals is not good. This picture is even worse for black Americans with disabilities and other members of minority groups.

Despite this unfavorable climate, research demonstrates that disabled individuals can work with appropriate education, job training and support services, including assistive technology.

As Senator Simon eloquently stated in his recently published book, "Let's Put America Back to Work," putting people to work is not going to be accomplished through some sudden, single, dramatic move. Creating the right kind of tomorrow is much like creating a mosaic with a host of small pieces all essential to the final picture.

I believe that my experience as an employer, mother, and student aptly demonstrate the delicate yet important role community support and training can make in the life of a disabled individual.

My name is Nina McCoy. I am currently the Director of an Independent Living Center being formed under the auspices of United Cerebral Palsy of Indiana. I am a single parent, raising a teenage son. In 1971, I became disabled due to an automobile accident. Since that time, I have struggled to live independently in my own community.

Despite my having graduated from college with highest distinction, I have worked only five of the last 16 years since becoming disabled. Much of the time I have been seriously under-employed. I have faced attitudinal barriers from employers who did not believe I had the ability to work. I have been confronted with environmental barriers that kept me in my home and out of the workplace. I have also been challenged by the economic burden of severe disability in which a significant portion of my earnings goes towards hiring personal care attendants and household help.

The disincentives to employment can be so great that many individuals with severe disabilities find it more economical to stay at home and receive Social Security disability income or welfare. However, the stagnant quality of their lives of idle dependency damages their self esteem and fills them with frustration. Their potential as wage earners and active participants in community life is thwarted.

Perhaps the scenario of my daily life as a person with a severe disability will help you to understand the support services that are necessary for a person with a severe disability to be employed.

In order for me to get out of bed and function at all, I need the services of a personal care attendant to help meet all of my personal care needs. My attendant bathes me, dresses me, and takes care of my bodily functions. She assists me into my wheelchair and helps me with my personal grooming. I pay for my own attendant care from my earnings. Last year, I earned $12,000. Without significant financial help from family, I would have had to stop and go on welfare to support my son and myself. In fact, last year at one point I put my house up for sale in order to try to meet my financial needs.

On a typical work day, I drive myself to work in my van which has been outfitted to meet my needs. Before I was able to drive myself, I had to pay someone to drive me wherever I needed to go. This became very expensive. However, it was much less expensive than using a private wheelchair transportation service at the rate of $60 round-trip and more reliable than the paratransit system in my community. The cost of modifying my van was paid for by the State of Indiana Rehabilitation Services Administration. If I did not have an accessible van, I truly do not know how I could be employed.

Once I am at work, I am able to perform my job independently due to assistive devices and rehabilitation engineering. My desk has been raised so that my chair can easily slide under it. My telephone receiver has a special handle on it that makes it easier for me to pick it up and hold it.

These modifications illustrate how, through creative problem solving, rehabilitation engineering enables individuals with disabilities to function more independently on the job, in training programs, or in the home. This is accomplished through the development of assistive aids, adaptive devices, and restructuring of work and/or learning environments and routines. Through such one-of-a-kind problem solving interventions, individuals with disabilities strengthen their abilities to function more independently and are often better able to participate in work and/or training programs. The net result for hundreds of Americans with disabilities is a life of greater independence and productivity.

Beyond a personal care attendant, I also need assistance with homemaking services. I must also pay for these services. Homemaking services assist me with cleaning my house, doing laundry, and preparing meals and other household chores. Although some individuals might consider these services a luxury, I do not. They are a necessity with me. Without such services, I would not be able to maintain my home for myself and my son.

When I have been unable to afford these services, my son has had to assume the role of my personal care attendant and homemaker. This has caused tremendous stress on our family.

Supported employment has proven that all individuals with mental retardation can work, when they are given the appropriate training and support services. These support services might include a job coach who provides individual on-site job training and might also teach the client, for example, how to get to and from work using public transportation.

As you can see, employment for disabled individuals does not only mean job training, but ensuring that a satellite system of support services are also in place. Adequate transportation to and from work is necessary to facilitate success on the job. For a person like myself, attendant care and accessible housing are also necessities.

This point has become even more apparent to me recently as I have begun to hire individuals to work at the Independent Living Center. I have interviewed a number of well-qualified severely handicapped individuals who have college degrees. It has really been a heart-rending and consciousness-raising experience for me to hear of their struggle to find employment and appropriate community supports. Many of these young college grads also feel they are not finding jobs due to the negative attitudes some employers have towards people with disabilities. I realize that there is no easy and quick solution to breaking down attitudes of employers, but I do believe there is a role that Congress and the Federal Government can play in this area.

The Federal Government can take a leadership role in educating employers about the available labor pool of qualified people with disabilities.

The Federal Government must continue to work together with community-based groups to train and place individuals in employment. Finally, and perhaps most importantly, Congress must pass the Civil Rights Restoration Act. Enforcement of strong civil rights legislation is an important factor in protecting from discrimination people who have historically been disenfranchised by society.

Senator Simon's recent book outlined a plan for putting Americans back to work. We acknowledge his inclusion of individuals with disabilities in his plan. His book raises awareness about the employment problem facing qualified disabled individuals, and we hope that this awareness will assist in finding solutions and guaranteeing employment opportunities for all disabled individuals.

As far as recommendations are concerned, we would first like to commend Congress for the action it took last session during the reauthorization of the Rehabilitation Act to ensure that more individuals with severe disabilities become successfully employed by including rehabilitation engineering as a service option and adding new funds in the area of supported employment.

We are very encouraged by the leadership Senators Tom Harkin, Paul Simon, and Lowell Weicker have shown this year in ensuring that individuals receiving supplemental security income were included in the Jobs for Employable Dependent Individuals Act.

The following are recommendations that CCDD believes should be part of a national plan that would guarantee employment opportunities for individuals with disabilities:

There should be an increase in the amount of funding provided to programs that train individuals for employment. Particular emphasis should be placed on programs that assist in training and placing individuals in jobs with an opportunity for career advancement.

There is a need for increased coordination between the Departments of Education, Labor, and Health and Human Services, particularly the Social Security Administration in administering their programs in the areas of education, employment, and job training. We believe that the Social Security Trust Fund remains an untapped resource to provide necessary funding for job training and community support services.

We believe that a plan must include mechanisms to ensure that all individuals whose potential to become economically independent through assistive devices and rehabilitation technology have access to such services.

Any plan to guarantee job opportunities must include accessible transportation, attendant care, and other necessary support services. It is evident that the lack of these support services contribute to the unacceptably high unemployment rate among people with disabilities.

And finally, we recognize that there are several barriers to employment that may not be addressed in a job program, but should be included in any effort to create employment opportunities. One barrier is the fear individuals who receive social security disability income have that they will lose their medical benefits once they become employed. Congress needs to make a commitment to ensure that people with disabilities have access to health care.

CCDD stands ready to work with you as you develop other creative approaches to providing job opportunities and support services to individuals with disabilities.

There is nothing more tragic than wasting human potential. Thousands of disabled Americans can become a part of the workforce with your leadership.

Thank you.

Senator HARKIN. Thank you very much.

[Additional material supplied follows:]

May 5, 1987

Senator Tom Harkin
Subcommittee on the Handicapped
Hart Senate Office Building 317
Washington, D.C. 20510

Dear Senator Harkin:

It was quite rewarding for me to testify before the joint hearing between the Subcommittee on the Handicapped and the Subcommittee on Productivity on Employment and Disability. I thought the testimony presented accurately described many of the difficulties individuals with disabilities face when trying to become employed.

During the hearing, you seemed particularly interested in the fact that I must pay for my own personal attendant care. Unfortunately, this is true for the major percentage of persons with severe disabilities who rely on attendant care to be active members of society. Recently the World Institute on Disability conducted an excellent survey on personal attendant care in the United States. It demonstrated that my story is occuring throughout the United States. I would therefore like to request that the executive summary of this survey is added to the hearing record as part of my testimony.

I was very impressed by your concern for individuals with severe disabilities. I know under your leadership as Chairman of the Subcommittee on the Handicapped, individuals with disabilities will be fairly represented in Congress.

Sincerely,

Nina McCoy
Nina McCoy

Senator HARKIN. Thank you again, all of you, for very fine testimony. I first of all just want to say to Mr. Callaway, does Andrea work for NewsBank?

Mr. CALLAWAY. No, sir, she does not. She works for a different company down in Norwalk.

Senator HARKIN. This is the one thing I got confused.

Mr. CALLAWAY. We have about eight or nine employees from either the STAR Workshop or ARI.

Senator HARKIN. Well, you are to be commended. You have had good success, you are very pleased.

Mr. CALLAWAY. We have had excellent success. They have been very productive to the workforce.

Senator HARKIN. Certainly there must be associations that you belong to in your area of New Canaan, Connecticut. I am not that familiar with that area, but in your dealings with other business people in your area, do you talk about this very much? Do you talk about your experience. Is there any kind of sort of cross-fertilization among CEOs and business people in your area about your success?

Mr. CALLAWAY. Regarding communication with the other companies on this matter, what we have done primarily in our communication with ARI or with STAR, and we will give them references to go to other businesses in the area, I might mention to them in the course of a conversation that we have an organization or a formal method of communication between us, not really.

What we have done is gone back and told, say, the STAR Workshop, say I think you ought to contact XYZ Corporation.

Senator HARKIN. I do not know, I just thought about this and, Dr. Anderson and all of the rest of you, we have always been approaching this from the standpoint of looking at it organizing—and I am going to have more to say about this—organizing individuals with disabilities and handicaps and to provide these programs for them, to get them into employment.

I am wondering if there should not be kind of another level—I do not want to say level, but sort of a mirror image of this on the employer side. Maybe we need a national association of employers of the disabled, sort of a national kind of association where they would be able to go out from the standpoint not of individuals with disabilities and handicaps, but of employers, business people, and talk to other businesses and say this has been our experience, we can help you and here are all the hurdles you have to get over, and here are the things you have to do to employ people with disabilities.

Maybe there is such an association and I have not heard of it, but I have never heard of one.

Ms. SUTER. Senator, in Illinois we have a State committee that has employers on it and we have regional committees of employers and job clubs, and we find, just as you are suggesting, it is a lot more credible for employers to talk to other employers about what is going on, and that questions are understandable and that is okay.

We also have a jobs program now in Illinois where we have a 1-800 number where employers can call in and list jobs and the qualification and then within 72 hours we refer a qualified person with a disability. So we have found employers to be very interested in this and helpful to gather them together and help spread the word.

Senator **Harkin**. I know the National Chamber of Commerce is meeting here in Washington this week, and I just began wondering, does the National Chamber of Commerce have any kind of organization within its body politic to go out and encourage businesses to employ the handicapped. I do not know. I just do not know. If they do not, it is something we have to encourage.

Ms. Anderson, again I just want to commend you for your very eloquent statement and to just follow up a little bit. You said, if I am not mistaken you said that 82.8 percent——

Ms. **Anderson**. You can modify that to 82 percent, sir, if you do not mind.

Senator **Harkin**. 82 percent of black disabled are unemployed.

Ms. **Anderson**. That is correct.

Senator **Harkin**. That is extraordinary. You talked about the civil rights movement which sort of led the prelude to the 1973 Act, and I guess I would like—at least I would say that it seems that the Civil Rights Act itself has enabled us to make great progress with the minority community of this country but it seems like something has happened here with the black disabled.

I just wonder why are they so stark, why is it so much different? We had the Civil Rights Act, for one, we had the Rehab Act, and blacks have made great progress under the Civil Rights Act, but why is this sort of falling through the cracks here on the blacks with handicaps.

Ms. **Anderson**. I do not think anybody has all the answers to it, but I think when we started out talking just a while ago about organizations of employers who employ disabled people, I think as a beginning we ought to ask every organization in the country of employers in every area to set aside one part of their meeting agenda for disabled people; that is rational and fair. We ought to have National Rehabilitation Month in September to focus on this problem, to bring everybody together, regardless of disability and regardless of where they are, so as a nation we can move in one direction at least once a year and focus on what we are doing in this area.

We need to set aside rehabilitation training centers in black communities, since transportation is the number one barrier to rehabilitation services, jobs, you name it. We do not have one single black operated, (as far as I know, there could be one but I know of none), rehabilitation training center in 1987, with all the funding that has gone on, not one.

We have had very few opportunities as black people to enter the industrial capitalist system, which is the best in the world. We need that opportunity for the disabled black people. All of these things are do-able, if more people would listen, hear and become more involved in reinvesting themselves. Their skills, sharing jobs and job information.

The information that we presented today, you are aware of it; however most people are not aware of it. We have to get the knowledge out there. In the media we need to do more to get disabled people before the American public to vitiak this social discomfort level. It is terrible! Of course, with blackness on top of disability, you potentiate the social discomfort level.

These are things we can do; and these are the things we must do, but most importantly, the employers. That is where the jobs are: to develop entrepreneurs, to develop jobs, to see that those who have control of jobs know about this and can communicate with each other so they can do more. I think this is where we need to start.

Senator HARKIN. Senator Simon?

Senator SIMON. If my colleague would yield, and unfortunately I am going to have to go to another meeting. First of all, I want to commend all of you.

What you just said, Ms. Anderson, about the media, one of the tragedies is—and I am sure my colleagues from Mississippi and Iowa would agree on this—we can have a hearing on a relatively frivolous topic and have five television cameras and all kinds of people there. Here we are talking about something that really is vital to millions of Americans, and do not think we have a single reporter covering this hearing.

We have got to get the message out to America much more clearly than we have up to this point. I simply commend you. You are building a small number of disciplines here who are going to go out and spread the word.

Let me just make a couple of other comments. One, Ms. Suter, you are absolutely right, my bill is not a substitute for other things. It is not the total answer. It is part of the answer. The Rehabilitation Act, for example, has done a tremendous amount.

Your suggestion that we get a representative of the disabled community on the executive committee I think is an excellent one and is one that we can follow through on.

The one suggestion that you have made and that others have made is that we ought to have something above the minimum wage in the way of pay. The difficulty here is as you increase the numbers, you also decrease the likelihood of getting something passed. That is one of the realities that I have to face.

And for a great many people, even the minimum wage, 32 hours a week, $464 a month is a tremendous lift over where they are right now. The average welfare payment, for example, in the State of Illinois is much more generous than many States. Average welfare payment in Illinois—I do not know what it is in Iowa, I do remember Mississippi—in Illinois it averages $289 a month. That is for a family on AFDC. In Mississippi, it is $92 a month. $464 is not a lot, but would be a tremendous improvement for a lot of people in their standard of living, their quality of life.

Again, I want to commend my colleague Senator Harkin for joining on this hearing, and Senator Weicker who was here earlier, and Senator Cochran, who is here now, for their interest, and these witnesses and the other witnesses for standing up. This is not an issue, as we have seen, that has drawn a lot of press, but it is an issue that really tests whether we are a civilized society, whether we respond to people who really have a need.

I commend all of you.

Senator HARKIN. Thank you, Senator Simon.

Senator Cochran?

Senator COCHRAN. Mr. Chairman, thank you. I want to join you both in expressing our appreciation to the witnesses who testified before the Subcommittees this morning. In reviewing the statements and listening to the comments that I have been able to hear, I am impressed that this is an issue area that needs the immediate attention of the Congress and I hope our Committee can make recommendations that will be helpful in moving us in the right direction to be sure that there are sensible and workable programs there to help reach these goals that we all share.

Thank you all for being here, and thank you, Mr. Chairman.

Senator HARKIN. Thank you, Senator Cochran.

I just have a couple of other things.

Nina, you received rehabilitative help. You were in an automobile accident, is that right?

Ms. MCCOY. Yes.

Senator HARKIN. Did you receive rehabilitative help through the State of Indiana?

Ms. MCCOY. Yes, I did.

Senator HARKIN. And now they have provided you with a van?

Ms. MCCOY. No. I purchased the van but they paid for the modifications.

Senator HARKIN. It has got a lift?

Ms. MCCOY. Yes, lift equipped and there is a steering device that I utilize and hand controls.

Senator HARKIN. Hand controls, hand brakes and that kind or thing?

Ms. MCCOY. Yes.

Senator HARKIN. There is a place where your chair locks in?

Ms. MCCOY. Yes.

Senator HARKIN. You bought the van, but they paid for the modification?

Ms. MCCOY. They paid for the modifications that were quite expensive. There is no way I could have done it.

Senator HARKIN. I do not know the total extent of your disabilities, but through your testimony you have to have someone obviously to get you prepared for the day in the morning and also at night also, I assume.

Ms. MCCOY. Yes.

Senator HARKIN. Now, that is very expensive.

Ms. MCCOY. Yes.

Senator HARKIN. Now, do I understand that you pay for that?

Ms. MCCOY. Yes, I do. I do not receive SSI, of course I do not receive SSDI. At the time when I was injured, I had not worked long enough under Social Security, I did not have enough quarters of coverage to be able to receive SSDI.

Senator HARKIN. How old were you when this happened?

Ms. MCCOY. I was 23, but I had worked in a lot of the social programs, the Great Society programs that Lyndon Johnson had initiated, whereby at the time they were not covered under Social Security.

Senator HARKIN. I see. So the person, the nurse or whoever it is that you have employed to do this, do you have to pay for that out of your own pocket?

Ms. MCCOY. Yes, I do.

Senator HARKIN. How can you do that?

Ms. MCCOY. Sometimes I barter. Most recently, I bartered with someone, I said, okay, you come and provide X number of hours of personal care assistance and you can live in my home, and we bartered that way, but most of the time—it has only been with the financial assistance of my family, primarily my mother that I have been able to survive and continue to work and be productive.

Senator HARKIN. You have your own home?

Ms. McCOY. Yes, I do.

Senator HARKIN. And in that home you have a teenage son?

Ms. McCOY. A teenage son, yes.

Senator HARKIN. One child?

Ms. McCOY. One child.

Senator HARKIN. Your teenage son lives there, so it is you and your son.

Ms. McCOY. And he has had to assume over the years many what I would call inappropriate roles in terms of assisting me in order that I can function. As I said, at times when I absolutely did not have the money or did not have enough money—in some States, I am not certain about Illinois, but I believe Illinois has a personal care attendant program whereby they are able to subsidize individuals with disabilities in order to help them pay for this kind of service. Indiana does not.

Senator HARKIN. You say we have that?

Ms. McCOY. Illinois has that.

Senator HARKIN. Illinois has that.

Ms. McCOY. And other States do.

Senator HARKIN. Where do you get the money for that?

Ms. SUTER. I could talk for hours on this. It is a significant problem. We have State funds that we have a program called home services and it is Medicaid reimbursable. We use State funds to provide attendant care for people to live independently in their homes as long as it is cheaper than living in a nursing home, which it is. It is a third of the cost. Besides the humaneness, it is a third of the cost of living in a nursing home, so it makes economic sense as well.

We are just at the tip of the iceberg on a national level. We need a national attendant care policy.

Senator HARKIN. And you made $12,000 a year?

Ms. McCOY. Yes. Fortunately, with the new position that I have, I am much more financially independent and not under as great a financial strain as I have been in the past.

Senator HARKIN. Are you familiar at all with any of the veterans programs that the VA provides for the disabled?

Ms. McCOY. Not specifically, no.

Senator HARKIN. You would probably both be amazed and probably justifiably angry. I have a nephew who is a quadriplegic.

Ms. McCOY. I am quadriplegic.

Senator HARKIN. You have a little bit more use of your arms than he does, a little bit more. His neck was broken about the fifth or the fourth, I forget, some place in there. He has some use of his arms, but he has a van like you do and he is able to go out. He is now going to school, but he received his injury in the military and the amount of help and assistance that the Veterans Administration gave has just been phenomenal. It has been wonderful. Without it, he could not have done it.

Ms. McCOY. Right.

Senator HARKIN. He does not come from a wealthy family. He is from a low income family. But they have done all the things, the van, the home, the independent living, and he has a nurse every morning who takes care of him and he goes off to school and does some other things and takes care of him at night, and that is all picked up by the Veterans Administration. The whole tab is picked up.

Again, certainly he was serving his country in the military, we do have an obligation to that, but it also seems that we have an obligation to individuals who serve their country in other ways. We do not all serve the country in the military, we serve it in other ways, and I just think if we can do it for that select group we ought to expand that kind of support and assistance that we have to cover all other individuals that have these disabilities.

I am just amazed that you are able to do that.

Ms. McCOY. Senator Harkin, I would like to make one other comment, if I may——

Senator HARKIN. Surely.

Ms. McCOY [continuing]. Concerning discrimination that is felt by all people with disabilities and in particular by members of minority groups, black Americans with disabilities, that the discrimination comes in attitudes that employers have.

Mr. Taylor, if I have his name correct, stated that the primary barriers to employment of people with disabilities were the lack of education and training. These are extremely important barriers, but I believe strongly that the negative attitudes that many employers have towards people with disabilities, their fears and their stereotypes, are much more significant barriers to employment or as great a barrier to employment as lack of training and lack of education.

Senator HARKIN. I think that is right. I think that way, too. It has to do with what I mentioned earlier about being uncomfortable, not knowing and that kind of thing.

Ms. McCOY. When I was employed two and a half years ago by the City of Indianapolis, in my interview the interviewer stated to me, "Nina, we have been discussing for years hiring a person with a disability and, to be honest with you, we feel very uncomfortable about it," but in their honesty we were able to have an honest dialogue and I told them, "Well, I feel uncomfortable, also, because I don't know what to expect," and in the process of my being employed with the City of Indianapolis for two and a half years, those attitudes just melted away. During the term of my employment, several other people with disabilities were hired and I think that is what happens—people's attitudes change.

Sue mentioned, I believe, that the responsibilities of the job coaches and the professional people who were part of their supportive employment program, were diminished because fellow employees were willing and able to provide the types of services and support that are necessary for people with severe disabilities to be employed, as they became more relaxed and as their perceptions were changed from negative to positive about people with disabilities, and that will happen and that will happen across the country. It will happen through this bill if it is enacted.

Senator **Harkin**. Well, I will end it on that note. Thank you all for coming. Andrea, thank you for coming down from Connecticut. We are most appreciative, and I can assure you that we will do everything we can to get the bill passed.

[Additional material supplied for the record follows:]

National Council on the Handicapped
800 Independence Avenue, S.W.
Suite 814
Washington, D.C. 20591

202-267-3846 voice
202-267-3232 TDD

An Independent
Federal Agency

June 10, 1987

Senator Tom Harkin
Chairman, Subcommittee on the Handicapped
Room 113
Senate Hart Office Building
Washington, D.C. 20510

Dear Senator Harkin:

Thank you for your invitation to provide comments on the Guaranteed Job Opportunity Act and the general problems of employment facing persons with disabilities. Although we have no specific comments about the Guaranteed Job Opportunity Act, we are very pleased to submit the enclosed report on employment issues and recommendations for your review.

The National Council on the Handicapped focused on the area of employment in the 1986 special report, "Toward Independence", which includes several recommendations that will enhance employment opportunities for persons with disabilities. We believe that employment is an especially important determinant of independence and quality of life for persons with disabilities.

We appreciate the opportunity to have our views on employment and the barriers to employment faced by persons with disabilities considered. If we can answer any questions or provide additional information to the Subcommittee, please do not hesitate to contact us.

Sincerely,

Sandra S. Parrino

Sandra S. Parrino
Chairperson

Enclosure

National Council on the Handicapped
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**An Independent
Federal Agency**

NATIONAL COUNCIL ON THE HANDICAPPED

REPORT ON EMPLOYMENT ISSUES RELATED TO PERSONS WITH DISABILITIES

June 10, 1987

National Council on the Handicapped
800 Independence Avenue, S.W.
Suite 814
Washington, D.C. 20591

202-267-3846 voice
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An Independent
Federal Agency

REPORT ON EMPLOYMENT ISSUES RELATED TO PERSONS WITH DISABILITIES

The National Council on the Handicapped appreciates this opportunity to discuss the general problems of employment facing persons with disabilities. As you are aware, the Council is an independent Federal agency comprised of 15 members appointed by the President and confirmed by the Senate. Congress has statutorily charged the Council with reviewing all laws, programs and policies of the Federal Government which affect persons with disabilities and making such recommendations as it deems necessary to the President, the Congress, the Rehabilitation Services Administration, the National Institute on Disability and Rehabilitation Research and other Federal agencies and officials. Although many government agencies relate to the needs and concerns of persons with disabilities, the National Council on the Handicapped is the only Federal agency with such cross-cutting responsibility for disability issues — regardless of age, disability type, employment potential, economic need, or other individual circumstances.

Over the past three years, the National Council on the Handicapped has conducted a series of forums throughout the United States in order to receive input from persons with disabilities, parents, service providers, experts and other knowledgeable individuals concerning the priority needs of persons with disabilities. Employment heads the list as one of the major concerns of persons with disabilities in this country. Recognizing the seriousness of barriers to employment opportunities for persons with disabilities, employment was selected as one of the ten areas in the Council's report, Toward Independence, submitted to the President and Congress in February, 1986.

In addition, the Council initiated two Harris Polls. The first Harris poll examined attitudes and experiences of persons with disabilities, including questions in the area of employment. As a result of the findings from the first Harris Poll, a second poll was conducted of employers, "Employing Disabled Americans."

For most Americans, employment is a major prerequisite to economic self sufficiency. Employment is an essential key to successful adult integration into community life. Various forms of work are frequently associated with greater independence, productivity, self-esteem, and social and financial security. In our society, success and quality of life are often measured in terms of paid employment. For persons with disabilities, work is no less significant. In fact, employment for persons with disabilities is critical in determining independence, self-sufficiency and quality of life.

Living independent, productive lives is the goal of many persons with disabilities. Yet for millions of Americans with disabilities, this goal has been little more than a dream. Advancements over the last twenty years, such as the enactment of legislation (the Rehabilitation Act, Education for All Handicapped Children Act, Developmental Disabilities Act, Job Training Partnership Act, Targeted Jobs Tax Credit, Section 190 of the Tax Code, Employment Opportunities Act) and private sector initiatives such as return-to-work programs and projects with industry, have accounted for an increase in the number of persons with disabilities in the labor force.

However, there is much that remains to be done in order to insure equal opportunity and full participation in society by all Americans. Persons with disabilities account for approximately one-sixth of the nation's population. According to the 1980 Census, approximately 22.7 million working age Americans (16-64) have physical or mental disabilities that limit employment. Of that number, 15.1 million reported disabilities that prevented them from working. At the time of the Census Survey, 4.6 million (or 20%) of the 22.7 million persons reporting a work disability were employed in the labor market. The number of unemployed persons with a work disability amounted to 0.6 million. More than three-fourths of all persons reporting disabilities were not in the labor force.

The Harris Poll findings confirm these statistics. The first survey indicated that "not working is perhaps the truest definition of what it means to be disabled: two-thirds of all disabled Americans between the age of 16 and 64 are not working. Only 1 in 4 work full-time, and another 10% work part-time. No other demographic group under 65 has such a small proportion working, including young blacks."

Another significant finding from the first Harris Poll was that 66% of working age persons with disabilities who are not working want to have a job. What are the reasons for these high rates of unemployment and underemployment if sixty-six percent of working age persons with disabilities want to work? What accounts for these persons not being hired?

According to the Harris Poll of employers, there are several major barriers that exist to employment for persons with disabilities, these are:

- Forty-seven percent of working age persons with disabilities who are not working, or working part-time, say that employers won't recognize that they are capable of doing a full-time job.
- Forty percent of this group say that a lack of available jobs in their line of work, or their inability to find jobs, is an important reason why they are not working full-time.
- Thirty-eight percent of disabled persons say that undereducation and a lack of marketable skills are important reasons why they are not working full-time.

- About 3 out of 10 (28%) say that a lack of accessible or affordable transportation is an important barrier to work for them.
- And 2 out of 10 (23%) of those not working, or working part-time, say that they don't have needed equipment or devices to help them work easier or communicate with other workers.

Another significant barrier to employment for persons with disabilities is discrimination by employers. One out of four (25%) working-age disabled persons say that they have encountered job discrimination because of their disability. There have been concerns expressed about how employment nondiscrimination regulations would apply to persons with disabilities.

One concern is that employers are opposed to statutory prohibitions of employment discrimination against persons with disabilities. The Louis Harris and Associates poll of employers (representing equal subgroups of small, medium, and large businesses) was conducted to determine their opinions on such issues. By a substantial majority, employers recognized the need and indicated their support for nondiscrimination provisions protecting individuals with disabilities. Three-fourths of company managers interviewed reported that they believe that persons with disabilities often encounter job discrimination, and over 70% stated that civil rights laws should protect persons with disabilities.

A related concern is that it is very burdensome for employers to provide equal employment opportunities for persons with disabilities. The Harris poll of employers has reaffirmed prior studies that have consistently found that persons with disabilities make good or better than average employees. Based upon employers' responses, the Harris organization concluded, "Overwhelming majorities of managers give disabled employees a good or excellent rating on their overall job performance," and further, "Nearly all disabled employees do their jobs as well or better than other employees in similar jobs." Employees with disabilities were rated as good or better than their nondisabled counterparts in regard to willingness to work hard, reliability, attendance and punctuality, productivity, desire for promotion, ability to take supervision, and leadership ability.

What about the costs of employing a person with a disability? Are job modifications for employees with disabilities very costly? The Council has examined existing studies of workplace accommodations provided for individuals with disabilities and concluded that accommodations are usually minor and inexpensive (see Toward Independence, Appendix, p. A-48). A 1982 Department of Labor study of workplace accommodations concluded that accommodation is "no big deal." The Harris poll of employers verifies the results of the earlier studies; the poll found large majorities of managers (approximately 75%) reporting that the costs of making accommodations are not expensive. While nearly one-half of companies reported that they had made some worksite modifications, an overwhelming majority stated that the costs of accommodations rarely drives the cost of employing a person with a disability above the average range of costs for other employees.

Finally, the Council wishes to note that many businesses have been willing to make their facilities accessible to and usable by persons with disabilities. Such changes have not proven to be exorbitantly expensive nor disruptive to business. Making facilities architecturally accessible benefits not only persons with disabilities but also many other customers, including elderly individuals, people pushing strollers and shopping carts and pregnant women. The Council is aware that many State and local governments have seen fit to mandate architectural accessibility as part of their building codes and ordinances. Obviously, architectural accessibility is not an impossible or unachievable goal.

The extremely high unemployment and underemployment rates for persons with disabilities have had substantial impact upon their lives. The first Harris survey indicated that disabled Americans are much poorer than non-disabled Americans. Half of all disabled Americans (50%) aged 16 and over have a household income for 1984 of $15,000 or less. Among non-disabled Americans, only 25% have household incomes in this bracket. One-fourth of persons with disabilities live in households with an annual income of $7,500 or less.

It is evident that if these persons are not working and cannot find employment, they must find some way to survive. For the most part, the majority of persons with disabilities not working and out of the labor force must depend on insurance payments or government benefits for support.

While it is true that employment opportunities have improved for persons with disabilities through the educational, training, independent living, and rehabilitation programs existing in this country today, there is still a large segment of the disabled population who desire to work but for whom employment still remains a distant goal. Cost savings have already and will continue to be realized by increasing the financial independence of many people with disabilities. The Federal Government and the private sector must make a concerted effort to overcome the attitudinal, transportation, physical and communication barriers that exist so that all persons with disabilities who want to work can work. It is the view of the National Council on the Handicapped that our entire society benefits from initiatives to secure increased opportunities for persons with disabilities.

Towards Economic Independence: A Goal for Disabled Black Persons in the United States

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6 • Frequency and Distribution of Disabilities Among Blacks: Preliminary Findings

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Abstract

The present study was designed to identify and assess the frequency, distribution, and impact of various disabilities among black Americans. Twenty-seven (27) agencies—8 state and 19 private—from the following targeted cities comprised the sample: Washington, DC; Atlanta, GA; New York, NY; Gary, IN; Los Angeles, CA; Little Rock, AR; Detroit, MI; and Jackson, MS. The research findings clearly substantiate evidence of some unique features of the status of black disabled individuals. Selected disabilities analyzed, using cross tabulations and chi-square statistics, suggest significant clusters of black clients only as the comparison relates to the distribution of blacks in the larger population of the designated areas. When analyzed across ethnic groups, the percentages of these disabilities for whites exceed those for blacks by 200% and sometimes 300%. Also, when the contrast is based on ethnic group membership across all regions, only sickle cell anemia is significantly more prevalent among blacks, and there is greater variability with regard to the incidence of disability and ethnicity-based regional distribution. Other findings relative to earnings and mental retardation, together with the delivery of services to blacks, call attention to the need for further investigation and for remediation.

BACKGROUND

While it is true that handicapped individuals who are members of racial and ethnic minorities suffer the same indignities as other handicapped individuals, there are special and unique problems that these individuals face because of the lack of awareness of their cultural differences (Thornhill, 1983). In addition, prejudice and racial discrimination continue to exclude a great number of minorities (particularly blacks) from full participation in all aspects of society (Stedman, 1977; Bowe, 1983; Walker et al., 1984).

The problem of black handicapped individuals is indeed complex. Not only do blacks have to live with excessive economic burden, but education is frequently not available to them. As a result, they have fewer opportunities for education and for earning decent incomes. Moreover, access to their homes, stores, schools, transportation, and the general community facilities can only be achieved through the use of extreme measures and often with the involvement of at least another person (Miller, 1984).

Merton Gilliam (1981) gives firsthand examples of prejudices he has experienced as a double minority (i.e., being black and handicapped). Gilliam said he grew up in the black ghetto of Cincinnati during the Depression and was constantly subjected to pressures and criticism in public schools. In his quest for employment, he suffered humiliation and rejection. "Nobody wanted to hire a guy on crutches, employers claimed that they would have insurance problems," he tells us.

During his college years, Gilliam observed that, of the 80 disabled students who were sponsored by rehabilitation or other programs, blacks received the least services:

> Public transportation was not available to the physically handicapped who used wheelchairs and crutches, and the cost of special transportation was excessive. The few facilities that are available to the handicapped are frequently set apart so that the individual has to be treated as a special case.

Clearly, the need for research which responds to the needs of minority populations with handicapping conditions has been substantiated. Evidence that minority populations (blacks in particular), have unique handicapping problems and have been inadequately served in rehabilitation programs is overwhelming (National Institute of Handicapped Research, 1981).

However, no comprehensive research has been conducted to indicate the number of handicapped individuals within the black population and to identify these unique needs. It is essential that research strategies be implemented which begin to address problems and issues specific to the successful rehabilitation of disabled minorities.

METHODOLOGY

Purpose

This study, along with two other research investigations, was designed to establish empirical research as a means of identifying and assessing the frequency, distribution, and impact of various disabilities among black Americans. The emphasis here is the identification and delineation of significant clusters relative to the rehabilitation status and needs of blacks as compared to other ethnic groups within eight select geographic areas of the United States.

The profile and results embodied in this research report cover only the initial elements of the study. More comprehensive reports will be given subsequently.

Description of Participating Agencies

Initiated during the 1983-84 project year of the "Howard University Model to Improve Rehabilitation Services for Minority Populations with Handicapping Conditions," this study examined disability distribution in a selected sample. Table I contains a profile of the 27 agencies comprising this selected sample based on predetermined research sites which constitute regional representation. The following cities were the targeted sites: Washington, DC; Atlanta, GA; New York, NY; Gary, IN; Los Angeles, CA; Little Rock, AR; Detroit, MI, and Jackson, MS. The rationale for this selection is that a substantial number of blacks reside in these cities. It should be noted that the sample population represents agencies and clients within the larger metropolitan areas within up to a one-hundred-mile radius.

See Table II for ethnic population distribution in the respective metropolitan areas (these figures were taken from the 1980 Population Census).

Data were collected during the period January to October 1984 via a survey format through the utilization of a two-part questionnaire which included three appendices. The questionnaire was mailed out to respondents. Eight public and 19 private agencies participated in this study. The total client population was approximately 282,000, which constitutes 87% for state agencies and 13% for private agencies. This statistic reflects some duplication since many public agencies often contract out clients to private agencies after evaluation. The ethnic composition of the sample is 36% black, 56% white, and 8% for other ethnic groups.

General Design and Analysis

The research instrument consisted of a two-part, twenty-four item questionnaire developed and validated through the cooperation of rehabilitation professionals from the following groups: the project's National Advisory Committee, the Local Task Force (which consists of representatives from agencies in the District of Columbia metropolitan area), and the Research Committee of the Council of State Administrators of Vocational Rehabilitation.

Types of Analyses

Part I of the questionnaire generated descriptive information on agencies surveyed, including staffing and types of services provided. These descriptive character-

TABLE I

AVERAGE CASELOAD OF AGENCIES PARTICIPATING IN NATIONAL SURVEY

LOCATION	PRIVATE PARENT ORGANIZATION	NO OF COUNSELORS	NO OF CLIENTS	AVG CASELOAD
Arkansas	Department of Human Services	132	3345	93
California	Human Resources Center	4	700	100
California	Parent Auxiliary	1	15	17
California	Parent Auxiliary	1	50	50
California	Parent Auxiliary	8	55	6
California	State of California	635	93589	148
District of Columbia	Department of Human Services	69	13507	200
Georgia	Department of Human Services	3	199	30
Georgia	Department of Human Services	82	12144	148
Indiana	———	148	22644	153
Michigan	League—Goodwill	3	434	15
Michigan	League—Goodwill	217	16381	96
Michigan	League—Goodwill	635	93589	148
Michigan	Michigan Rehab. Services	16	844	67
Michigan	Michigan Rehab. Services	20	144	80
Michigan	Michigan Rehab. Services	47	3941	111
Michigan	Jewish Volunteer Services	4	345	25
Michigan	Jewish Volunteer Services	7	167	19
Mississippi	Department of Human Services	86	24203	281
New York	Assoc. for Chn. W/Ret. M/Dev.	30	1000	20
New York	Department of Education	—	74725	—
New York	Federation of Jewish Phil.	22	1015	25
New York	Federation of Jewish Phil.	29	435	15
New York	Vera Ins. of Justice, Inc.	6	153	20
New York	Health & Hospital Services	—	—	—

TABLE II

ETHNIC DISTRIBUTION IN THE TARGETED AREAS ACCORDING TO THE 1980 POPULATION CENSUS

CITIES	BLACKS NO.	%	WHITES NO.	%	TOTALS
Atlanta, GA	498,826	24.5	1,506,640	74.3	2,029,710
Detroit, MI	890,532	20.45	3,376,800	77.5	4,353,413
Gary, IN	126,350	19.65	491,274	76.4	642,781
Jackson, MS	126,202	39.3	192,547	60.0	320,425
Little Rock, AR	82,865	21.0	306,058	77.7	393,774
Los Angeles, CA	943,968	12.6	5,073,617	67.8	7,477,503
New York, NY	1,940,628	21.27	6,117,497	67.07	9,126,346
Washington, DC Metro Area (SMSA)	853,719	27.8	2,072,934	67.7	3,060,922

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istics were examined across state and private agencies with cross-tabulations. Part II of the research instrument facilitated the collection and analysis of the following types of data: a) the frequency of various types of disabilities and b) a comparison of client earning levels at referral and closure. Utilization was also made of a chi-square statistical measure in the anaylsis of data.

Research Questions

1. With reference to the descriptive characteristics of the sample surveyed, (a) how many clients were served in the respective agencies for Fiscal Year 1983, and what was the average caseload per counselor? (b) what types of services were provided? (c) what was/were the principal source(s) of funding?
2. What is the ethnic breakdown of the sample populations?
3. Of the 18 identified disability groups, which ones, if any, are significantly more prevalent among blacks than among whites?
4. Are there significant differences, based on ethnicity, with respect to these 10 selected disabilities?
    - Blindness
    - Diabetes
    - Orthopedic Impairment
    - Sickle Cell Anemia
    - Amputee
    - Epilepsy
    - Substance Abuse
    - Cardiovascular Diseases
    - Mental Retardation
    - Visual Impairment
5. What percentage of the total sample constitutes mental retardation for all ethnic groups in both private and public agencies?
6. Is there a relationship between disability and ethnicity with respect to regions?
7. What is the level of earnings of clients at referral and closure by ethnicity?
8. Given the five regions:
    West: California
    Midwest: Michigan, Indiana
    Mid-Atlantic: Washington, DC
    Northeast: New York
    South: Georgia, Mississippi, Arkansas
    where are the most significant clusters in the 10 major disabilities for nonwhites located?

Results

An analysis of Part I of the survey instrument yielded descriptive characteristics of the sample (including staff personnel, clients served, types of services provided) which are as follows:

1. Eight public and 19 private agencies showed a grand total of over 1,660 counselors (not including New York State) and 282,000 clients served during the 1983 fiscal year. Of these, the public agencies account for 70% of the counselors and 87% of the clients served. Table I gives a more detailed breakdown of these variables and their respective frequencies. Much of the data from New York State and Harlem Hospital are currently being further analyzed; therefore, all of the findings are not fully reported. The remaining data will be included in a subsequent report to be given at a later date.
2. State agencies located in larger, more highly populated states carry proportionately larger clientele. Examples are the State of California with approximately 94,000; New York State, 74,725; Mississippi, 24,000; and Indiana, 23,000. Georgia and the District of Columbia also have relatively large clientele—some 12,000 and 13,500 respectively. (See Table I.)
3. With respect to average caseload per counselor, private agencies seem to have an advantage. For instance, private agencies have a grand mean of 48 clients per case worker. That is over 300% as many. It must be noted, however, that these 156 clients might constitute a spurious statistic, since state agencies often contract out services to private agencies so that clients are often included in state agency intake and after evaluation, they are then referred to private facilities for the provision of specific services such as training. Private agencies include organizations such as Goodwill Industries and the Association for Retarded Citizens.

Another variable was the primary source of funding for the respective agencies. These represent three principal types: state-federal matchings, state-supported and private contributions. As might be expected, all eight public agencies fell under the category of state-federal matchings. For the private agencies, there is a great deal of overlap since many of these agencies get their financing from combined sources. For instance, as many as 56% of the agencies reported support from state-federal matchings. Yet, many of these are also represented in the 33% financed by private contributions and also in the 39% receiving contributions from sources other than the three mentioned above. (See Table III.)

A detailed examination was also made with respect to the types of agencies serving disabled populations in the targeted areas as well as the services offered. Tables IV and V contain an overview of these data. Pre-eminent among the types of agencies are vocational, vocational rehabilitation, educational social service, mental health, private and non-private residential and nonresidential, non-profit and independent living centers. The types most frequent in our sample are vocational (12%), vocational rehabilitation (23%), educational (6%), non-profit (12%), and private (9%). (See Table IV.)

The data reflect the delivery of a wide range of services. The following are among the most frequent types of services provided by the participating agencies: medical diagnosis and treatment, psychological diagnosis and treatment, psychiatric diagnosis and treatment, vocational and educational counseling, peer counseling, academic reinforcement, vocational assessment, occupational and physiotherapy, job training and placement. A large number of agencies also provide vocational assessment (i.e. 21 agencies, or 78%, offer this type of service). Consistent with this, there are a similarly large number of agencies offering job training; for example, 70% of our sample offer this service and 56% provide job placement. With reference to vocational education and counseling, another 56% offer academic reinforcement (see Table V for further breakdown.)

In Section II (of the research instrument), selected disabilities analyzed by ethnic groups reveal some interesting contrasts. Of the 18 disability categories listed in the survey questionnaire, the categories with the largest number of clients were "other" totaling 20,844 (this category includes clients with multiple handicaps) and "mental retardation" totaling 18,114. Of the mentally retarded clients, 14,727 were served by state agencies and 3,831 were served in private agencies. (Mental retardation represents clients clearly identified as mentally retarded—approximately 13% of the sample population. Nevertheless, it must be stated that it is likely many of the clients identified under the "other" category may also be mentally retarded, since this category includes the multiply handicapped.) The data show that 6,989 of the 14,727 mentally retarded clients (48%) in the public agencies were black. Similarly, 1,919 of 3,836 mentally retarded clients (50%) in the private agencies were black (See Table VI). A similar pattern was shown for whites. Mental retardation was 48% and 41% respectively for state and private agencies.

Other major disabilities showing significant clusters for nonwhite groups in public agencies are blindness (32%), sickle cell anemia (95%), orthopedic impairment (25%), substance abuse (30%), and cardiovascular disease (30%). Amputee, diabetes and epilepsy also represent proportionate clusters for blacks and other minorities. It should be noted, however, that while each of the disabilities cited is significantly high among blacks, sickle cell anemia is the only one which has a lower rate of manifestation among white clients in the sample. In response to research question 3, of the 18 disability groups selected for the sample, only sickle cell anemia is more prevalent among blacks than among whites when the comparison is based on ethnic group membership across all regions. However, the data bears out a positive answer to research question 4, since the significant differences in the prevalence of disability do exist based on ethnicity.

With respect to the most significant clusters in the 10 major disability groups across state and private agencies, in response to research question 4 (Is there a relationship between disability and ethnicity with respect to region?), the following results were observed: Table VI indicates that sickle cell anemia, mental retardation and cardiovascular disease all have significant clusters across state and private agencies. Blindness, diabetes, amputee and substance abuse (all in the 30 to 30 + percentage range) suggest significant clusters also. This, however, is reflective of the distribution of blacks in the sample population which is 36%. All of the other disabilities named in research

TABLE III
TYPE AND SOURCE OF SUPPORT FOR AGENCIES PARTICIPATING IN NATIONAL SURVEY

TYPES OF AGENCIES	FEDERAL/STATE MATCHING		STATE SUPPORTED		PRIVATE CONTRIBUTIONS		OTHER	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
State = 8	28	100						
Other = 19	10	56	6	33	6	33	7	39

TABLE IV
PROFILE OF SAMPLE AGENCY CATEGORIES

TYPE OF AGENCY	AGENCIES					
	STATE AGENCIES		PRIVATE AGENCIES		OTHER	
	Number	Percent	Number	Percent	Number	Percent
Correctional	0	0	0	0	0	0
Educational	0	0	6	100.0	6	6.7
Government	4	80.0	1	20.0	5	5.6
Hospital	1	100.0	0	0	1	1.0
Independent Living Center	1	20.0	4	80.0	5	5.6
Mental Health	0	0	5	100.0	5	5.6
Non-Private	1	50.0	1	50.0	2	2.2
Non-Profit	0	0	0	0	0	0
Non-Residential	1	25.0	3	75.0	4	4.5
Private	0	0	9	100.0	9	10.1
Profit	0	0	0	0	0	0
Residential	1	20.0	4	80.0	5	5.6
Social Service	0	0	6	100.0	6	6.7
Vocational	1	16.7	5	83.3	6	6.7
Vocational Rehabilitation	7	30.4	16	69.6	23	26.0
Total	18		71		89	100.00

TABLE V

SUMMARY OF TYPES OF SERVICES OFFERED BY SAMPLE AGENCIES

TYPE OF SERVICES	AGENCIES					
	STATE AGENCIES		PRIVATE AGENCIES		OTHER	
	Number	Percent	Number	Percent	Number	Percent
Academic Reinforcement	4	27	11	73	15	6
Independent Living	5	36	9	67	14	6
Job Placement	6	40	9	60	15	6
Job Training/Ret	7	37	12	63	19	8
Medical Diagnosis	6	55	5	45	11	5
Medical Treatment	6	67	3	33	9	4
Occupational Therapy	5	50	5	50	10	4
Peer Counseling	3	33	6	67	9	4
Physical Therapy	5	63	3	37	8	3
Psychiatric Diagnosis	6	60	4	40	10	4
Psychiatric Treatment	6	46	7	54	13	5
Psychology Diagnosis	6	43	8	57	14	6
Psychology Treatment	6	46	7	54	13	5
Recreation Facilities	5	45	6	55	11	5
Social Work	1	10	9	90	10	4
Transportation	6	43	8	57	14	6
Other	2	40	3	60	5	2

question 2 are also proportionately significant (see Table VI).

It is important to note, however, that these percentages constitute significant proportions only as they relate to the distribution of blacks in the sample and in the larger population of the designated areas. When analyzed across ethnic groups, the percentages of these disabilities for whites are two and sometimes three times the proportion for blacks. Examples of these phenomena are reflected in the fact that among the blind, 32% were black and 56% were white. Likewise, of the substance abuse clients, 30% were black and 61% were white. Another example of these comparisons is the fact that in public agencies epilepsy was 28% among blacks and 64% among whites. (See Table VI for review of these data.)

While this pattern of concentration of black handicapped clients seem to be characteristic of the sample for most regions (West, Midwest, and Northeast), for most of the disability clusters reported above, there are several exceptions however. The chi-square statistical procedure showed a significant relationship (above and beyond the .01 level) between disability and ethnicity with respect to the regions from which the sample was drawn (see Table VII). The pattern of disability in relationship to the clients' ethnicity was less consistent for the Southern and Mid-Atlantic regions than for the other three regions.

An examination of Table VII for the West, Midwest, and Northeast regions, reveals similar ratios of the incidence of visual impairment, amputee, and epilepsy between blacks and whites to those found in Table IV for the overall sample. However, there is greater variability with regard to the incidence of disability and ethnicity based regional distribution. For example, mental retardation in the Southern region is reported as 69% among blacks as compared to 28% among whites (whereas it was reported as about equally distributed within the overall sample for both public and private agencies). Visual impairment is reported as being about three times as high among blacks in the Mid-Atlantic and Southern regions. This pattern was reversed in the overall sample. Likewise, substance abuse is reported to be 70% among blacks as compared to 23% among whites in the Midwest. The Mid-Atlantic region reported overwhelmingly high proportions for blacks for each of the disability categories.

With reference to the economic status of clients at referral, the data indicate that generally as the income levels increase, the percentage of blacks in the respective categories decreases. Further, some 32,410 of the 109,142 (or 30%) of clients with no earnings are black (see Table VIII). With respect to earnings of clients at closure, the data show some marginal decrease across all ethnic groups (except blacks) in the no income category. The percentage of blacks in this category went up by 2%. However, there is a significant upward trend in the percentages at the higher income levels for black clients. For instance, in the less than $50 per week category, the percentage of blacks dropped from 29% at referral to a mere 5% at closure, while in the $200+ category, the percentage rose from 12% to 15%. (See Tables VIII and IX for these comparisons.)

DISCUSSION

The study clearly has substantiated further evidence of some unique features of the status of black disabled individuals. Indeed there are important findings that call attention to further examination and perhaps remediation.

The current study provides an overview of the types and level of rehabilitation services in eight metropolitan areas throughout the United States. The findings include a profile of eight public and 27 private agencies. It also provides comparisons of the distribution and frequency of disability among the sample population. An analysis of 1980 census data reveal the incidence of disability among blacks in the general population to be almost twice as high among blacks as it is among whites—14% as compared to 8% (Bowe, 1983). However, the breakdown of disability among the clients in the current study in the majority of the categories identified for the study, with the exception of mental retardation (which was almost evenly distributed) and sickle cell anemia (which was found almost exclusively among blacks), was reported at levels two or three times higher among whites than blacks. It was noted, nevertheless, that a large number of blacks were identified under the other categories which included multiple handicaps. The distribution of various disabilities by

TABLE VI
NUMBER AND PERCENT OF CLIENTS FOR SELECTED DISABILITIES BY ETHNIC GROUPS

DISABILITY	STATE AGENCIES									PRIVATE AGENCIES								
	BLACK		WHITE		HISPANIC		OTHER		TOTAL	BLACK		WHITE		HISPANIC		OTHER		TOTAL
	N	%	N	%	N	%	N	%		N	%	N	%	N	%	N	%	
Amputee	539	33	919	57	89	6	65	4	1612	93	44	100	49	2	1	14	7	209
Blindness	1273	32	2201	58	216	6	248	6	3936	234	35	281	42	-	-	158	23	673
Cardiovascular	1302	36	2022	57	106	3	152	4	3582	234	46	214	42	23	5	34	7	505
Cerebral Palsy	249	26	647	68	36	4	17	2	949	33	31	63	60	5	5	4	4	105
Diabetes	394	33	708	59	61	5	47	4	1210	62	44	70	49	2	1	8	6	142
Digestive Disorders	615	36	1054	61	38	2	25	1	1732	67	52	59	45	1	1	3	2	130
Epilepsy	560	28	1285	64	126	6	45	2	2016	111	41	146	54	8	3	5	2	210
Hearing Impairment	1018	20	3398	67	313	6	330	7	5059	227	33	362	53	25	4	68	10	682
Learning Disabilities	598	26	1437	63	216	10	26	1	2277	188	37	308	69	18	3	1	-	513
Mental Illness	3160	22	10038	70	685	5	393	3	14276	402	18	1494	66	214	10	142	6	2242
Mental Retardation	6989	48	7035	48	384	3	319	2	14727	1919	50	1558	41	215	5	144	4	3835
Orthopedic Impairment	5143	25	13617	67	1196	6	524	3	20480	706	43	779	49	35	2	89	6	1629
Respiratory Conditions	264	35	433	57	36	5	33	4	766	30	30	54	55	4	4	11	11	99
Sickle Cell Anemia	238	92	10	4	-	-	10	4	258	43	90	-	-	-	-	5	10	48
Speech Impairment	158	33	258	54	52	11	10	2	478	23	31	45	61	3	4	3	4	74
Substance Abuse	3278	30	6559	61	739	7	201	2	10777	371	35	667	62	1	0	31	3	1070
Visual Impairment	246	24	618	61	111	11	36	4	1011	60	25	158	67	9	4	9	4	236
Other	9499	55	5738	33	474	3	1683	10	17398	1413	43	1513	49	9	3	158	5	3095

TABLE VII

SIGNIFICANT CLUSTERS IN THE MAJOR DISABILITY GROUPS ACROSS REGIONS (STATE AGENCIES ONLY)

DISABILITY		WEST: CALIFORNIA				MIDWEST: INDIANA				MID-ATLANTIC: DC				NORTHEAST: NEW YORK				SOUTH: GA, ARK., MISS.			
		B	W	H	O	B	W	H	O	B	W	H	O	B	W	H	O	B	W	H	O
Blindness		321	1043	197	48	82	82	9	1	238	31	5	30	28	68	—	2	608	161	5	168
	%	20	65	12	3	47	47	5	1	78	10	2	10	27	71	—	2	64	18	1	18
Visual Impairment		40	124	105	10	2	9	3	—	69	5	2	12	20	121	—	2	165	359	1	11
	%	14	44	38	4	14	64	21	—	78	6	2	14	14	85	—	1	31	67		2
Ortho. Impairment		1006	4225	1165	222	100	96	12	—	745	29	19	123	938	4722	—	52	2358	4545	—	127
	%	15	64	18	3	48	46	6	—	81	3	2	13	16	83	—	9	34	65	—	2
Amputee		62	197	84	22	9	14	3	0	79	2	2	11	97	299	—	13	292	406	—	19
	%	17	54	23	6	35	54	12	—	84	2	2	12	24	73	—	3	40	57	—	3
Substance Abuse		641	1872	734	43	39	13	3	0	986	80	8	89	591	1397	—	19	1021	3197	5	50
	%	20	57	22	1	70	23	6	—	85	7	6	8	29	70	—	1	24	75	.1	1
Mental Retardation		486	995	365	31	51	36	5	—	624	55	10	67	1371	4063	—	41	4687	1888	4	180
	%	26	53	19	2	55	39	5	—	83	7	1	9	25	74	—	1	69	28	.5	5
Sickle Cell Anemia		50	1	—	1	9	1	—	—	40	1	—	4	55	8	—	0	84	—	—	6
	%	98	2	—	2	90	10	—	—	89	2	—	9	87	13	—	—	93	—	—	7
Cardiovascular		171	439	106	30	14	13	0	1	360	4	5	81	193	679	—	3	584	88	—	51
	%	23	59	14	4	40	46	—	4	80	.8	.1	18	22	78	—	.3	38	60	—	3
Epilepsy		88	317	126	15	19	16	—	—	52	6	3	15	132	641	—	5	209	305	—	5
	%	16	58	20	3	54	46	—	—	68	8	4	20	17	82	—	1	40	58	—	2
Diabetes		54	167	58	9	6	9	—	—	108	2	3	24	72	319	—	2	154	213	—	12

TABLE VIII
EARNING STATUS OF CLIENTS AT REFERRAL BY ETHNIC GROUP ACROSS STATE AND PRIVATE AGENCIES

MEAN WEEKLY INCOME	BLACK	%	WHITE	%	HISPANIC	%	OTHER	%	TOTAL
No Earnings	32410	30	69351	64	4215	4	3166	3	109142
Less than $50	316	29	724	65	37	3	32	3	1109
$50–$99	472	26	1288	70	35	2	52	3	1847
$100–$120	358	38	541	57	29	3	17	2	945
$151–$199	146	22	496	74	10	2	19	3	671
$200 +	281	12	2115	87	40	2	3	1	2439

TABLE IX
EARNINGS STATUS AT CLOSURE BY ETHNIC GROUPS ACROSS STATE AND PRIVATE AGENCIES

MEAN INCOME WEEKLY	BLACK	%	WHITE	%	HISPANIC	%	OTHER	%	TOTAL
No Earnings	6378	32	12183	62	731	4	410	2	19702
Less than $50	639	5	12419	94	16	.1	23	.2	13097
$50–$99	618	25	1722	71	75	3	26	1	2441
$100–$125	423	3	872	62	80	6	25	2	1400
$126–$150	1535	30	3322	65	199	4	57	1	5113
$151–$199	748	22	2378	71	188	6	39	1	3353
$200 +	1016	15	4745	71	406	6	523	8	6690

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ATTENDING TO AMERICA

PERSONAL ASSISTANCE FOR INDEPENDENT LIVING

Executive Summary Of

THE NATIONAL SURVEY
OF ATTENDANT SERVICES PROGRAMS
IN THE UNITED STATES

World Institute on Disability
April 1987

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EXECUTIVE SUMMARY

ATTENDING TO AMERICA:
PERSONAL ASSISTANCE FOR INDEPENDENT LIVING

A SURVEY OF ATTENDANT SERVICE PROGRAMS IN THE UNITED STATES FOR PEOPLE OF ALL AGES WITH DISABILITIES

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Special recognition must be given to the following WID staff members who made this project successful: Curtis "Kitty" Cone, who did the initial planning of the questionnaire and conducted part of the interviewing; Nancy Ferreyra, who conducted interviews, prepared the bibliography, assisted in data analysis, and answered correspondence and information requests; Hale Zukas, who was engaged in planning, editing and policy development at all stages of the project; Sandy Swan, who lent her computer and research skills and common sense; Marian Conning, who typed all the versions of the report, kept track of funds, offered sound suggestions and generally held down the fort; Helga Roth, who cheered us on and helped with editing; Joan Leon, who wrote the original proposal for the project and directed it through all its various stages; Mary Lester, who prepared the graphs; and Judy Heumann and Ed Roberts, who provided the ideological/philosophical overview for the project and the report. In addition, we would like to thank Carol Silverman, Ph.D., Instructor in Sociology at the University of California, Berkeley, who all but donated her research and computer skills to this project.

Simi Litvak
Berkeley, California
January, 1987

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* Individuals who use personal assistance services

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PREFACE

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Independence and self-reliance are strongly held American values. They are the key to any claim that we are a truly open society. For it is reasoned that if anyone would only try hard enough, s/he could eventually succeed -- the Horatio Alger myth. That such concepts have also crept into our rehabilitation literature should be no surprise. Thus traditional stories of successful rehabilitation continually stress the individual's ability to overcome his/her particular chronic disease or disability. In fact, success in rehabilitation is often equated with high scores on The Adaptation in Daily Living (ADL) scale, a scale that measures an individual's ability to do many personal care activities by him/ herself.

The founders of the Independent Living Movement scored poorly on the ADL scale. They were people on whom traditional providers of care had given up -- people for whom not only a productive life but even a meaningful one was deemed impossible. Neither they nor their families accepted the judgments of experts and in their struggle and their answer the Independent Living Movement was born. Their stories of success are different. Without negating the importance of personal qualities and the improvement of one's functional abilities, they emphasized the necessity of removing architectural barriers, changing societal attitudes, and using help whenever and wherever they could get it.

In all the years I've heard Ed Roberts speak (To those who don't know him, he's one of those "rejects" mentioned above -- a man, post-polio, who uses a respirator and a wheelchair and was deemed unworthy of California's rehabilitation dollars. He went on to co-found The California Center for Independent Living and later the World Institute on Disability and in-between became California's Director of the Department of Rehabilitation and a MacArthur Fellow) he has introduced his personal assistant by name and briefly detailed the latter's role in Ed's being "here." Ed makes the gesture to concretize a concept of independence which is a cornerstone of the Independent Living Movement (DeJong, 1983).

For Ed and others in the Independent Living Movement, independence is not measured by the quantity of tasks one can perform without assistance but the quality of life one can have with help. People have often gotten help from others but it was often given in the context of duty and charity (Scotch, 1984). Help in the context of Independent Living is instead given within the framework of a civil right and a service under the control of the recipient -- where, when, how and by whom.

This concept has long been argued about but little studied. DeJong (1977) surveyed the services of one state; DeJong and Wenker (1983) did a comparison of several; and Laurie (1977), a timely national overview. Within the last three years DeJong (1984) and Ratzka (1986) have provided in-depth descriptions of the progress and promise in the Netherlands and Sweden. This current report, prepared by Simi Litvak and sponsored by the World Institute on Disability, is a much needed American response -- a detailed survey of some 154 attendant service programs in the U.S. serving almost a million people.

The 17-page questionnaire measured their development, administration, funding sources, and degree of conformity to the ideal Independent Living Model. Despite the wealth of data, this report is no mere compilation of tables and statistics. It is an extraordinarily self-critical document, telling the reader what it gathered well, poorly, and not at all. It names names and articulates issues. While echoing the need for further information, in a series of recommendations it lays down the gauntlet of what must be done to make all our citizens independent. While documenting the programs already in existence, it also describes the underserved and points to the future (the ever increasing number of newborns with disabilities as well as increasing aging of our population). It is clear that many who will read this report will not at present have a disability. But if the data on aging and genetics are correct, it is unlikely that anyone reading it will not in their lifetime have to face the issue for him/herself or in his or her families.

At long last, we now have some baseline data. Personal Assistance for Independent Living lays down how far we have come and how far we have yet to go.

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SECTION I

INTRODUCTION

The need for community-based personal assistance services for independent living and the lack of a nationwide policy direction and mechanism for meeting that need has become an issue of major significance for disabled people of all ages who feel these services are critical to their ability to control their lives. Along with people who are disabled and their families, advocates, legislators and social policy makers throughout the United States and abroad have placed personal assistance services at home and in the community on the global agenda.

Personal assistance involves assistance with tasks aimed at maintaining well-being, personal appearance, comfort, safety and interactions within the community and society as a whole. In other words, personal assistance tasks are ones that individuals would normally do for themselves if they did not have a disability.[1] Central to this definition is the precept that personal assistance services should be controlled by the user to the maximum degree possible.

Our research leads to the conclusion that, for every person who is actually receiving community-based, publicly-funded personal assistance services, there are more than three people who need such services but who are not getting them. Specifically, we estimate -- on the basis of data from the National Health Interview Survey and surveys of the institutionalized population -- that 3.8 million people in this country need personal assistance services. According to the survey which is the subject of this report, however, only approximately 850,000 people currently receive personal maintenance and hygiene, mobility and household assistance services from publicly-funded, community-based programs. Thus, almost three million people in need are going unserved.

Moreover, almost all of the service programs which do exist are inadequate. Seldom do they offer the combination of personal assistance services necessary to enable people who are disabled to function satisfactorily at home and in the community. Distribution of these programs is uneven across the United States, eligibility criteria vary widely, and direct service providers are generally poorly compensated.

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[1] These tasks include: 1) personal maintenance and hygiene activities such as dressing, grooming, feeding, bathing, respiration, and toilet functions, including bowel, bladder, catheter and menstrual tasks; 2) mobility tasks such as getting into and out of bed, wheelchair or tub; 3) household maintenance tasks such as cleaning, shopping, meal preparation laundering and long term heavy cleaning and repairs; 4) infant and child related tasks such as bathing, diapering and feeding; 5) cognitive or life management activities such as money management, planning and decision making; 6) security-related services such as daily monitoring by phone; and 7) communication services such as interpreting for people with hearing or speech disabilities and reading for people with visual disabilities.

Before discussing the results of the survey, it is important to make clear the particular philosophical orientation that has framed the conduct of the research and the interpretation of the results. What follows in this introduction then is the Independent Living view of personal assistance services, why they are needed, what they are and who can benefit from them. The World Institute on Disability (WID) is suited to present this view for several reasons. WID was established by several founders of both the Independent Living Movement and the first Center for Independent Living in Berkeley, California.

As a mechanism for obtaining input from other experts in the field during this study, WID established an Attendant Services Advisory Committee comprised of leading activists in the field and in the Independent Living Movement. Finally, at the request of the National Council on the Handicapped, WID played the major role in organizing the National Attendant Care Symposium held in July, 1985, under NCH sponsorship; most of the recommendations presented at the end of this report came out of that Symposium.

The Need for a National Personal Assistance Program and Policy

The need for personal assistance services has grown over the last few years. Due to advances in medical technology, there has been a sharp increase in the number of young people with extensive disabilities in the U.S. population. Many of these young people face a full lifetime in a nursing home, dependence upon their families until the parents became too old to provide the needed services, or dependence upon service programs that encourage dependence and poverty. This population has become the driving force behind the creation of the Independent Living Movement and its efforts to gain publicly-funded personal assistance services with maximum user control.

The ever-increasing number of people in the U.S. population who are old has expanded the disabled population needing personal assistance, since loss of functional ability (i.e. ability to perform activities of daily living) often accompanies the illnesses and injuries that occur more commonly among older people.

The demand for personal assistance services has also expanded as a result of the growing emphasis on keeping and taking disabled and elderly people out of institutions. This emphasis was largely born out of efforts by advocacy groups representing people with a variety of disabilities (mental retardation and "mental illness" in particular) during the 1960's and gained strength with the emergence of perhaps its most natural adherent, the Independent Living Movement, in the 1970's.

It was clear to these activists that the successful deinstitutionalization of people with extensive disabilities, as well as the prevention of institutionalization and avoidance of dependency, rested substantially on the availability of personal assistance services in the community. However, the existing service system lacked a strong community-based orientation and did not offer services that foster independence.

The demand for personal assistance services has grown also because older people and their advocates are waging a struggle to develop a "continuum of long term care" where nursing homes are only one of several elements, rather than the primary locus of assistance for older people with functional limitations.

A fifth factor increasing the demand for personal assistance services has been the transformation of the U.S. family. A majority of working-age women now hold jobs outside the home. Rising divorce rates, shrinking family size and the growth in single-parent families have all contributed to the family's decreasing ability to provide personal assistance services for disabled members of all ages.

Finally, during the late 1970's and early 1980's, the federal and state governments became very interested in the replacement of institutional care by community-based services, which include personal assistance services, because this seemed to be a more economical way to treat disabled people unable to manage completely for themselves.

The need for community-based personal assistance services, then, is clearly on the national agenda. Despite the growing need and interest, however, the federal government has neither promoted the development of these services nor established a coherent policy on the issue. Jurisdiction over various personal assistance programs and policies is divided among numerous federal agencies and congressional committees. There is no coordinated "system".

In the absence of a comprehensive federal policy and funding for personal assistance services, some states have tried to piece together several federal funding sources into a state program; a few other states have tried to meet the need by developing their own policy and program; still other states have done nothing in the area and, as a result, have almost no personal assistance services available.

The lack of a comprehensive, coordinated national policy often means that, even where the services are available, users either have to maneuver through a fragmented maze of service programs in order to put together a package of required services, make do with services that are inadequate, or remain in an institution, nursing home, or isolated at home with their families.

In addition, those programs that do exist usually provide assistants only for poor people. This means that people either need to have incomes below the poverty level or earn enough not only to support themselves but also to pay for the assistance that they need as well. The resulting need to earn a relatively high income thus discourages people from working, thereby increasing, rather than decreasing, public expenditures on the disabled.

The Concept of Personal Assistance and Attendant Services

This report covers solely attendant services. Attendant services are a subset of the full range of personal assistance services disabled people need to function independently in the community (see footnote 1, page 1). Attendant services include assistance with personal maintenance, mobility and household maintenance tasks. Often these services are separated into groups and offered by separate programs. To compound the confusion, they are called by other names as well: personal care services, personal care attendant services, home health aide services, homemaker services, chore services.[2]

Our conception of appropriate personal assistance services goes much deeper than a simple listing of tasks, however. Of major importance is that personal assistance service users have the opportunity, if desired, to exercise as much control as they are capable of handling over the direction and provision of these services - i.e. who does them, how, and when. This element of self-determination lies at the core of the Independent Living model of service delivery. The model rests on the philosophy that to be independent means to be empowered and self-directed. Independence does not mean that one must be able to perform all tasks alone without help from another human being. This distinction may appear to some as not very significant, but it is absolutely crucial for people of all ages with extensive disabilities. Such individuals may be able to perform few if any daily living tasks without assistance, but this fact has no bearing on their right to determine when, where and how these tasks are performed. For people who are unable or unwilling to totally direct their own services, the option to receive services from assistants trained and supervised by a public or private agency should be available.

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[2] In discussing and defining personal assistance and attendant services, we deliberately avoid the use of the term "care" (e.g. attendant care, personal care, etc.) because it implies that the disabled person passively receives the ministrations of the attendant. In our view, care is what sick people receive. Disabled people are not sick and, therefore, do not need "care". They need an assistant.

In addition, personal assistance services are personal assistance services even when they are performed by members of one's family. Consequently, family members who provide such services at the request of the user should be entitled to receive compensation for their labor. People with extensive disabilities may require 20 or more hours of assistance per week, the equivalent of a half-time job. This amount of assistance, which is quite beyond what family members would do for each other if none were disabled, clearly cuts into the time that would otherwise be available for outside employment and other familial duties. The vast majority of people who provide volunteer personal assistance in the U.S. are women, a situation which increases the incidence of poverty among women. Clearly, substantial governmental expenditures are often avoided when families maintain disabled members outside of institutions, but providing these services on a volunteer basis often entails considerable costs: the family's earning potential is significantly reduced and the person with a disability is inhibited from achieving full independence. Having to depend upon the charity or good will of family and friends places the user in a dependent rather than an independent position. In addition, when family members are forced by economic or other reasons to provide attendant services, the resulting stress can lead to psychological or physical abuse of the person who is disabled.

The Independent Living conception of attendant services also recognizes the need to include in regular service delivery systems both emergency and short term services, commonly referred to as respite. Emergency attendant services provide assistants in cases of emergency, for example when attendants cannot perform their duties because of sickness or personal difficulties and not enough notice can be given to make other arrangements. In cases where a disabled individual lives alone and has no relatives or friends who can help out at the last minute, emergency back-up services are crucial.

Short term services are intermittent attendant services replacing family members or regular assistants on a scheduled basis. They enable the individual who is disabled to get both the assistance needed and an opportunity to be independent of the family for brief periods. Short term personal assistance also allows the family member to leave the home for anything from a few hours for errands to an evening out or several weeks' vacation.[3]

In summary, while we recognize that personal assistance services by themselves are not sufficient to enable people with disabilities to live to their maximum potential in the community, they are absolutely necessary to achievement of this goal.

Potential User Population for Attendant Services

The population of potential users of attendant services is large and diverse. It includes people of any age and with any disability - be it physical, sensory, intellectual or mental- which results in long-term functional limitations that impair an individual's ability to maintain independence.

The perception of who can use personal assistance has evolved over the years. It has long been generally accepted that people with physical disabilities often need assistance. More recently, however, people with mental or intellectual disabilities but no physical limitations have also begun to use assistants to help them function effectively in the community. Such assistants may help people pay bills, keep financial records, make up shopping lists, deal with landlords, etc.

The user population includes people of all ages. There has been a tendency to treat older people with functional limitations, disabled working age people and disabled children as three distinct groups with totally different service needs. However, older people who have functional limitations are disabled in the same sense that other disabled people are - that is, they are limited in their ability to perform life-maintaining tasks without assistance. Whether young, middle-aged or old, disabled people may be at risk of isolation, physical harm and institutionalization because of their functional limitations. The causes of these limitations may vary somewhat, but the effects are often very similar. Furthermore, older people with functional limitations have as much need to maintain control over their lives and the services they receive as younger people with disabilities. Thus, not only are personal assistance services often the appropriate answer for many older people with functional limitations or disabilities, but the principles of the Independent Living Movement apply to them as well.

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[3] Short term services are part of the continuum of personal assistance services. Some people need these services daily, some need them several times a week and others need services on occasions when family members have to leave the home. Short term services serve the person who is disabled, breaking the chain of mutual dependency between the disabled family member of any age and the rest of the family. Power dynamics in families can be changed by another person coming into the home for brief periods. Because families may have to provide major amounts of service, the disabled individual may be made the victim of the family's stress. In these situations, the disabled individual needs a break from the family and the routine equally as much as the family. Short term personal assistance should be seen as an opportunity for the disabled individual to get out of the house, go on visits, see a film or even take a trip. Usually the family uses these services to go away and the disabled persons stays at home or - even worse - is sent to a hospital.

If personal assistance has not been widely recognized as a means of preserving older people's independence, the use of non-family paid providers to foster independence in disabled children has hardly even been considered. Making such assistance available has several benefits. It can alleviate financial pressure on families by allowing parents to take outside employment. This is particularly true in cases where a child with a disability needs assistance throughout the day and there are no volunteer resources available.

Personal assistants for children can relieve the emotional strain that frequently develops within families as siblings (and sometimes parents) come to resent the disproportionate amount of time that parents must devote to a child who is disabled.

Providing personal assistants for children with disabilities also allows them a more normal process of development and maturation. It enables them to go places (thus gradually expanding their range of mobility), engage in recreational pursuits, and - particularly important during adolescence-interact with peers. Also, children with disabilities, assisted by an attendant, can begin taking on family chores and duties-such as setting the table or taking out the garbage - just as non-disabled children do as a normal part of growing up.

This list of benefits of providing attendants for children could go on and on. The primary point, however, is that the process of developing one's independence and self-management skills commences long before a person with a disability reaches adulthood. It is a process that occurs throughout the normal course of development of all children.

The population of potential attendant service users also includes people in various living arrangements and settings. People with functional limitations who live independently obviously need assistance. People living with their families also need assistance; whether in the form of occasional short-term service or on a regular basis, so that the disabled person has more independence and the family member, relieved of attendant duties, is free to work and/or maintain the home.

Attendants may also work for clients in various congregate living arrangements such as cluster housing and group homes. In these situations, attendants may be shared by several people, though this type of arrangement has drawbacks because it frequently means that the individual user loses control over when and how long the attendant is available. Finally, people can use personal assistance not only at home, but also at work, recreation and travel.

Corollary to this inclusive definition of who can benefit from personal assistance services is the understanding that a person's medical diagnosis has no bearing on his or her need for services. People with similar diagnoses may have dissimilar functional abilities and face different sets of environmental constraints. Determination of need for personal assistance is more appropriately based on a functional assessment which measures one's abilities and limitations in performing necessary activities of daily living within a particular environment.

Source of Funding for Attendant Services in the U.S.

Several federal and state programs currently provide funding and authorization for some part of the constellation of personal assistance services.

Medicaid: The bulk of Medicaid funds go toward hospital, nursing home and institutional care for low income people. There are wide variations from state to state in home and community-based service benefits offered and the groups covered, income eligibility criteria, cost sharing formulae and levels of provider reimbursement for home and community-based services. Almost all Medicaid home-delivered service programs are geared toward medically related services, the major exceptions being the Colorado, Massachusetts and New York programs which have found innovative ways to work within the Medicaid framework and still make it possible for individuals who are disabled to maintain a great deal of control.

Title XX - Social Services Block Grant (SSBG): Most states provide some sort of home based services with Social Services Block Grant funds, but few have developed comprehensive SSBG attendant services programs which encompass personal maintenance, hygiene, mobility and household assistance. California's In-home supportive services system (IHSS), with expenditures of $370 million in FY85-86 and a caseload of 111,300, is a notable exception.

Older Americans Act - Title III: Title III was designed to augment existing services and to develop new ones to meet the needs of people over 60. Included in these services are a very wide variety of personal assistance services. Federal regulations encourage the targeting of Title III funds to the poor. Because of funding limitations, however, it has not been a major source of attendant services.

Home and Community-Based Service Waivers: The Home and Community-Based Service Waivers - commonly known as Medicaid Waivers - were developed in 1979 to investigate ways to halt the growth of Medicaid nursing home and institutional expenditures by expanding home and community services for people with physical and intellectual disabilities, children, and older people.

An assumption underlying the waiver programs is that home and community-based services are less costly than institutional services. However, the Health Care Financing Administration (HCFA) argues that, since the number of people who would ordinarily be in a nursing home is limited to the number of nursing home beds which exist in any particular state (an amount which varies widely), then the number of people on the waiver must be limited to those who quite literally would be admitted to a nursing home if it weren't for the waiver. Since those who aren't admitted because of bed shortages somehow get their needs met in other settings by family and friends, the argument goes, the federal government has no responsibility to maintain these people.

In addition, the federal government required states not to spend on any one individual more than the average cost of what it takes to maintain people in nursing homes, less a certain percentage for room-and-board costs. This rule discriminated against people with extensive disabilities because the bulk of people in nursing homes are older people with fewer service needs and presumably lower average service costs. Responding to pressure, Congress has now changed this rule so that there is a two-tiered limit - one tier being the average cost of maintaining physically disabled people and the other the average cost of maintaining other nursing home residents. Contention over who can be covered by a Waiver has greatly slowed the pace of new Waiver approval and renewal of old ones by HCFA.

State and Locally Funded Programs: During the late 70's and 80's a number of states created programs funded entirely by state and local sources. Because these programs did not use federal dollars, they could allow disabled people to hire, train and, if necessary, fire their own assistants and also contained realistic cost-sharing formulae that allowed people with disabilities to work and still receive a personal assistant subsidy payment.

Veterans' Aid and Attendance Allowance: An "aid and attendance allowance" is furnished to veterans in addition to their monthly compensation for disability incurred during active service in the line of duty.

Overview of the Survey

This report is based on the results of a survey - conducted by mail or telephone from February 1985 to January 1986 - of administrators of every program in the United States (excluding Puerto Rico and the trust territories) which provided personal maintenance/hygiene and/or household assistance services on either a regular or respite basis to disabled people of any age.[4]

One-hundred seventy-three programs meeting these criteria were identified. Nineteen of these, for various reasons, are not included in the results presented here.

The questions addressed by WID's survey and by this report are the following:

1. What are the goals of the programs and how are they structured? What are their administering agencies, funding sources and eligibility criteria? What services are provided and who provides them?

2. How do the scope and quality of the service programs measure up? In particular, how well do they meet the criteria for an adequate attendant services system developed by the participants at the July 1985 conference in Washington, D.C. sponsored by the National Council on the Handicapped in conjunction with the World Institute on Disability?

3. Where do programs fall along the continuum between the Independent Living and medical models?
4. What is the degree of attendant service utilization, i.e. how many people are currently receiving some type of attendant services? How does this number compare to the number of people who could benefit from such services?

5. Are attendant services equitably distributed across the U.S.?

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[4] This survey did not, however, include programs which served exclusively people with mental disabilities (commonly termed "mental illness") and/or people with intellectual disabilities (mental retardation and similar conditions). Because of fragmentation of the service system, these programs are administered separately and would have required substantial additional resources to locate and survey.

SECTION II

SURVEY RESULTS

Program Goals, Administration and Funding

Program Goals

96% of the programs are directed at preventing institutionalization by making it possible to keep people in their own homes or communities.

66% of the programs are directed at containing the cost of long term care.

Only 10% of the programs are aimed at allowing people to work.

Number per State

Every state has a personal assistance service program of some sort. (This does not mean, however, that anywhere near all the people who need services are being served. Indeed, in all but a few states, most people in need of services are not getting them.)

On the average, there are three programs per state. The range is from one program in Arizona, Louisiana, North Dakota and Tennessee, to 6 each in Massachusetts, Missouri, New York and Ohio.

Program Age

The programs range in age from 32 years old to less than one year old.

56% of the programs were started after 1980. Almost half of these are waiver programs.

Administering Agencies

45% are administered by state level agencies having jurisdiction over welfare and social service programs. An additional 17% are administered by medical assistance and health departments.

27% are administered by State Areas on Aging.

State vocational rehabilitation agencies administer 7% of the programs.

Personal assistance services programs are administered directly by independent living programs in Maine, Nevada, North Carolina and South Dakota.

Funding Sources

More than 1/3 rely on Medicaid funds combined with state and, in some cases, local funds.

Less than 1/4 use Social Services Block Grant funds.

22% are funded entirely from state or local sources.

Only 8% of the programs function on a combination of federal funding sources.

Program Structure

Eligibility

Age

88% of programs serve people over 60 or 65 years old, 72% serve adults between ages of 18 and 64; and 45% serve children. 41% serve people of all ages.

Disability Groups

56% serve people with all types of disabilities. 26% serve only people with physical disabilities and those with brain injuries. 10% serve only those with physical disabilities.

Employment

16 programs encourage people to work; 6 require an individual to be employed; and 4 require that the person be employed a minimum of 20 hours a week.

Income

An estimated 50% of the programs had income limits at or below $5,250 (the U.S. poverty level for a single person in 1985). 36% of the programs have a graduated shared cost formula.

Other Eligibility Criteria

57% required that people be at risk of institutionalization, 42% required physician's orders.

Services

The basic minimum of personal maintenance and hygiene services are defined as feeding, bathing, dressing, bowel and bladder care, oral hygiene and grooming and transfers. The basic minimum of household maintenance services is light cleaning, laundry, shopping, and meal preparation and clean-up. The combination of these household and personal services makes up a basic attendant service program.

Ninety (58%) of the programs surveyed offered attendant services. Of these, 51 also offered catheter assistance.
12% offer personal services only.

25% offer household maintenance services only.

5% offer only respite services, but more than half of the programs included some sort of respite service.

Hours services available

101 (66%) of the programs offered services 7 days a week, 24 hours a day.

18 (12%) offered services 7 days a week, but less than 24 hours a day.

24 (16%) of the programs offered services less than 7 days a week and less than 24 hours a day.

Maximum amount of service allowed

Service maximums per user were expressed in hours or in terms of a maximum financial allowance.

54 (35%) of the programs expressed the limit in monetary terms with a range of $60/month to $1,752/month. The average was $838.

38 (27%) programs gave the maximum allowance in terms of hours. Hours ranged from 3 to 67/week with an average of 29 hours.

44 (29%) programs set no maximum monthly allowance.

Service Providers

Assistants can be divided into three groups, those who are individual providers, those who work for contract agencies and those who work for state, county or municipal governments. Many programs use more than one type of provider (Table 1).

TABLE 1

PROVIDER TYPE MIX (n=154)

	Programs	
Type of Provider	Number	Percent
Contract Agencies Only	54	35%
Individual Providers Only	33	21%
IPs and Contract Agencies	24	16%
IPs, Contract & Govt Staff	20	13%
Contract Agencies & Govt Staff	20	13%
Government Staff Only	3	2%

Provider types vary in terms of benefits and wages (Table 2).

TABLE 2

NUMBER OF BENEFITS AND AVERAGE HOURLY WAGE BY PROVIDER TYPE[a].

		Benefits		
Provider Type	Average Hourly Wage	Average Number	Benefits Range[a]	Mode
Government Workers (n=30)	$4.77	4.7	0-7	7
Contract Agency Workers (n=62)	$4.71	1.7	0-7	0
Individual Providers (n=60)	$3.74	.7	0-3	0

[a] Includes 1) vacation pay, 2) sick leave, 3) health insurance, 4) worker's compensation, 5) Social Security, 6) unemployment compensation and 7) transportation costs.

Provider modes vary in terms of the degree of consumer control allowed to train, pay, hire and fire attendant (Table 3).

TABLE 3

NUMBER OF PROGRAMS ALLOWING CONSUMERS
TO TRAIN, PAY, AND HIRE AND FIRE ATTENDANTS

Type of Provider	Train		Hire/Fire		Pay	
	#	%	#	%	#	%
Individual Providers (n=77)	48	62%	57	74%	31	40%
Contract Agencies (n=118)	15	13%	5	4%	1	1%
Government Workers (n=44)	4	9%	4	9%	0	0%

Individual Providers

A major advantage of the Individual provider mode, from the Independent Living Movement's perspective, is that it often gives more control to the consumer.

The primary disadvantage of the individual provider mode is that workers tend to be paid at or very close to the minimum wage, receive very few it any benefits and have a high turnover rate. Some administrators were opposed to the consumer taking charge of the training function because of potential liability problems, even though in 27 years of experience the California system (which does not require any training) has never been sued for negligence related to an independent provider.

Most of the individual provider programs have minimal regulations regarding providers. 22 required some formal training for assistants, 27 required assistants to be 18 or older. 26% of the programs said that the only requirement is that the consumer request an individual provider.

41 programs permit relatives to be paid under some circumstances (Table 4).

TABLE 4

CIRCUMSTANCES IN WHICH PROGRAMS ALLOW RELATIVES TO BE PAID ATTENDANTS (n=41)

Reason	Number	Percent
No one else is capable or available	13	31%
The relative is not legally responsible for the disabled individual	10	24%
Relative is prevented from working outside the home because no other attendant is available	9	22%
Relative does not reside in the same house	7	17%
Relative is not the spouse	7	17%
Any relative is okay	6	15%
No spouse, parent, child or son/daughter-in-law	4	10%
Niece, nephew, cousin okay	2	5%
No blood relatives or spouses	2	5%

Contract Agency Providers

The average hourly difference between the reimbursement rate and the attendant's wages was $4.08, almost a 100% mark-up for every hour of service.

Contract agency workers are usually trained. Trained assistants are appropriate for disabled clients who are unable to manage totally their personal assistant.

Government Agency Providers

Only 29% of programs utilize direct employees of the state or local government units and the number will probably decline further.

Determination of Services Allowed

Functional ability and services needed are the primary indicators used for evaluating the client. Service professionals, including case managers, social workers, nurses and program directors, were found to be the primary decision makers. Users have a voice in these decisions in only 11 (7%) of the programs.

Medical Supervision

25% of the programs require medical supervision by an R.N. or other health professional for all services.

33% of the programs require medical supervision for some services.

40% of the programs require no medical supervision.

Degree of Program Conformity to the Independent Living Model

Attendant programs can be arranged on a continuum defined by the medical model on one end and the Independent Living Model on the other. In the Medical Model a physician's plan of treatment is required along with periodic nursing supervision. Attendants are recruited by the contract agency. The attendant is ultimately accountable to the physician and the recipient essentially plays the role of patient.

In the Independent Living Model the attendant is managed by the user. No medical supervision is required. Attendants are recruited by the user, paid by the user and accountable to the user.

In order to see where the programs surveyed fit on the continuum, each program was given a score from zero to ten based on a count of how many of the following ten characteristics of the pure Independent Living Model the program incorporated:

1. No medical supervision is required;

2. The service provided is attendant service with catheterization, i.e. services offered include personal maintenance and hygiene, mobility and household assistance.

3. The maximum service limit exceeds 20 hours per week;

4. Service is available 24 hours a day, seven days a week;

5. The income limit is greater than 150% of the poverty level;

6. Individual Providers can be utilized by the consumer;

7. The consumer hires and fires the attendant;

8. The consumer pays the attendant;

9. The consumer trains the attendant.

10. The consumer participates in deciding on the number of hours and type of service he or she requires.

Figure 1 shows the distribution of the surveyed attendant programs along the continuum from Medical Model to Independent Living Model. Half of the states have programs that score 7 or better on the Independent Living Orientation Scale (Table 5). But, at the same time, it must be pointed out that half of the programs have scores of three or less.

Program Utilization and Expenditures

Number Served

Approximately 850,000 people received publicly-funded attendant services through 135 of the programs in the WID Survey. (This figure is an estimate because 16 programs could not report their caseload, 19 programs could not be interviewed, 9 programs were eliminated because the agency could not isolate figures for attendant services from other services, and two programs provided figures too late for inclusion.)

The proportion of the population receiving attendant services in any given state ranged from 0.01% to 0.87% of the population (Table 6). The total number of users represents 0.34% of the U.S.population.

Disabilities of People Served

Forty-six percent of the programs actually serve people with all types of disabilities; 28% served only people with physical disabilities and/or brain injury. Thirteen percent served only people with physical disabilities. These figures do not vary greatly from what administrators say programs will serve.

Ages of People Served

Twenty-three percent (142,562) of the people served are less than age 60 or 65. Seventy-seven percent (476,851) of those served are older than age 60 or 65.

Figure 1

DEGREE TO WHICH PROGRAMS CONFORM TO INDEPENDENT LIVING MODEL (n=147)

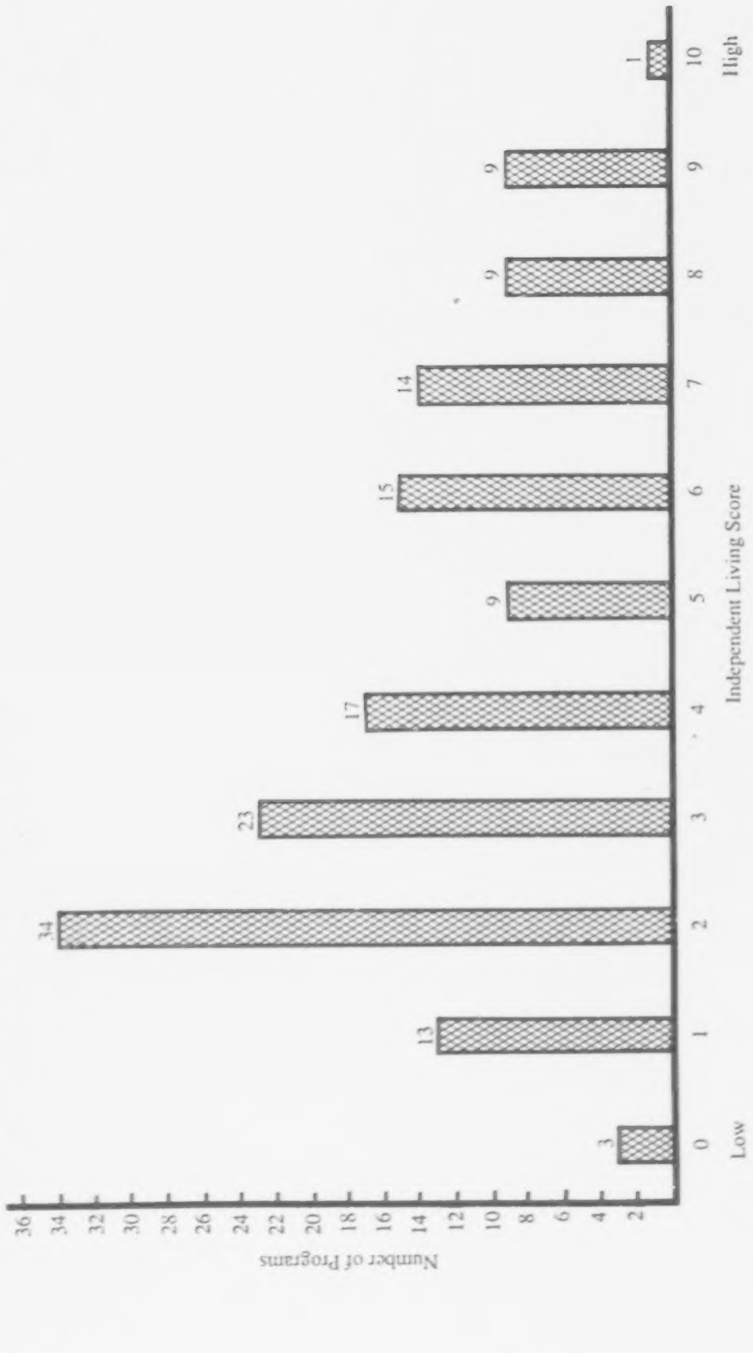

TABLE 5

PROGRAMS WITH THE HIGHEST INDEPENDENT LIVING ORIENTATION

Rating	State	Program Name
10	Pennsylvania	Attendant Care Demonstration
9	Maine	Home and Community-Based Waiver
	Maine	Homebased Care Program
	Missouri	Personal Care Assistance Program
	Nevada	Attendant Care Program
	Ohio	Personal Care Assistance Program
	South Dakota	Attendant Care Program
	Utah	Personal Attendant Care
	Vermont	Participant Directed Attendant Care
	Washington	Chore Services
8	Kentucky	Personal Care Attendant Program
	Maine	Attendants for Employed People
	Maryland	Attendant Care Program
	Michigan	Home Help
	Mississippi	Independent Living-A/C Pilot Pgrm
	Nebraska	Disabled Persons/Family Support
	New Hampshire	Adult Services
	Pennsylvania	A/C Services for Older Adults
	South Dakota	Attendant Care
7	Alabama	Optional Supplement of SSI
	Arkansas	Spinal Cord Commission
	California	In-Home Supportive Services Pgrm
	Connecticut	Essential Services Program
	Connecticut	Personal Care Assistance Program
	Illinois	Community Care Program
	Illinois	Home Services Program
	Maine	Attendants for Unemployed People
	Massachusetts	Independent Living Personal Care
	Massachusetts	Personal Care Program
	North Carolina	Attendant Care
	Oregon	In-Home Services/Project Independ.
	Wisconsin	Supportive Homecare Program
	Wisconsin	Family Support Program

TABLE 6
COMPARISON ACROSS STATES
OF EXPENDITURES AND TOTAL CLIENTS
OF ATTENDANT SERVICE PROGRAMS[a]

State	Total Number of Attendant Service Clients	Percentage of 1985 State Population Estimate	Total Expenditures (in thousands)
Alabama	24,016	.62%	$ 17,723
Alaska[b,d]	1,193	.30%	2,200
Arizona	1,500	.06%	1,696
Arkansas	5,225	.23%	10,285
California	150,805	.64%	345,445
Colorado[g]	8,867	.31%	14,719
Connecticut	10,816	.35%	23,108
Delaware	968	.16%	1,485
Florida[b,f]	22,858	.24%	21,386
Georgia[a]	6,747	.12%	7,612
Hawaii	1,709	.18%	2,875
Idaho	4,283	.45%	1,177
Illinois	16,301	.14%	33,734
Indiana	21,808	.40%	13,391
Iowa	12,605	.43%	7,849
Kansas[b]	9,057	.38%	6,137
Kentucky	7,329	.20%	6,065
Louisiana[c]			
Maine	6,013	.53%	4,804
Maryland	5,082	.12%	11,441
Massachusetts[b,d]	46,374	.81%	90,467
Michigan	43,933	.47%	69,653
Minnesota[e]	35,300	.87%	5,800
Mississippi	400	.02%	372
Missouri	31,209	.63%	14,659
Montana	6,248	.79%	1,969
Nebraska	5,429	.35%	3,286
Nevada	1,071	.13%	1,092
New Hampshire	3,893	.42%	3,087

State	Total Number of Attendant Service Clients	Percentage of 1985 State Population Estimate	Total Expenditures (in thousands)
New Jersey	1,850	.03%	3,809
New Mexico	2,200	.17%	7,384
New York	124,808	.71%	504,361
North Carolina	626	.01%	1,657
North Dakota	59	.01%	192
Ohio	26,359	.24%	46,942
Oklahoma	9,130	.30%	35,395
Oregon	10,041	.38%	15,330
Pennsylvania	59,995	.51%	22,338
Rhode Island	1,578	.17%	3,754
South Carolina	9,690	.31%	14,501
South Dakota	4,020	.58%	1,910
Tennessee[b]			875
Texas	68,880	.48%	108,288
Utah	522	.04%	1,048
Vermont	362	.07%	611
Virginia	5,000	.09%	14,191
Washington	10,167	.25%	22,735
West Virginia[a]	5,177	.27%	4,814
Wisconsin	15,600	.33%	25,953
Wyoming[c]			
Dist.of Columbia	3,285	.55%	8,853
TOTAL	850,388		$1,568,458

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[a] Data added from two additional programs from questionnaires received late from Georgia and West Virginia.

[b] Number does not include Title III recipients because administrator unable to isolate attendant services from adult day care, home-delivered meals, counseling and other Title III services.

[c] No data available.

[d] Alaska & Massachusetts figures do not include HHA programs. Decided they were strictly short-term.

[e] Minnesota does not include Personal Care Services figures.

[f] Florida does not include elderly waiver.

[g] Colorado does not include HHA program/could not separate ILP-delivered services from regular Medicaid program.

Expenditures

Total expenditures were approximately $1.6 billion, ranging from a low of $2,000 (a program serving 10 people) to a high of $458 million (a program serving 52,400 people). Average yearly expenditure per client was $2,862, with the median being $1,421.

As Table 6 shows, New York has the highest expenditure even though California serves the largest number. This reflects the fact that New York relies heavily on contract agencies whereas California uses more individual providers.

Expenditures by Funding Source

TABLE 7

TOTAL EXPENDITURES ON ATTENDANT SERVICES
BY FUNDING SOURCE (n=129)

Funding Source	$	%
Federal		
Title XIX		
Regular Program	384,740,000	25%
Waivers	19,294,000	1%
Title XX	320,703,000	21%
Title III	37,281,000	2%
Title VIIA	14,000	0%
Other Federal	52,372,000	3%
TOTAL FEDERAL	814,404,000	52%
Non-Federal		
State	617,732,000	40%
County/Municipal	84,438,000	6%
Other	13,004,000	1%
Client Fees	7,166,000	0%
Private	1,035,000	0%
TOTAL NON-FEDERAL	723,375,000	48%
GRAND TOTAL	1,537,779,000	100%

Expenditures on Attendant Services Not in the WID Survey

The Veteran's Administration aid and attendance allowance program paid $101 million to 8,493 veterans in 1984.

Some Developmental Disability and Mental Health Service funds are utilized to maintain individuals outside of institutions.

Many individuals who are disabled receive services from family and friends free of charge or pay for the services out of pocket.

No private health insurer pays for attendant services on a long term basis.

Availability of Services Across the United States

In 8 states, the full range of publicly-funded attendant services are not available for people with disabilities of any age. In 3 states services are available for some people but not others, depending on age.

In 39 states plus the District of Columbia, programs exist that offer attendant services to all age groups. These programs differ widely in their capacity to meet the needs of disabled people in their jurisdiction because of marked variations in eligibility criteria, services offered, maximum allowances, other rules and regulations, and, most importantly, funding constraints.

Thirty-four states have short term or respite available for all age groups, though the quality and quantity of the services available is not equivalent across these programs.

Need vs. Adequacy of the System to Meet That Need

Conducted by the U.S. Bureau of the Census, the Home Care Supplement to the 1979-1980 National Health Interview Survey (NHIS) interviewed a sample of civilian, non-institutionalized people in the U.S. over a period of two years. Respondents were asked whether they received or needed the assistance of another person in performing seven basic physical activities: walking, going outside, bathing, dressing, using the toilet, getting in or out of bed or chair, and eating.

Table 8 compares the NHIS estimates of need with the WID data on the number of people being served. This comparison indicates that 74,473 children who need personal assistance services do not get them from the public programs surveyed for this study. There are an estimated 758,938 working-age adults and 903,202 people 65 or older who need assistance but do not get it from public programs. All told, then, there are an estimated 2,134,111 non-institutionalized people who need personal assistance but do not receive it from publicly-funded attendant service programs.

If veterans are subtracted and an estimate of institutionalized people who could live at home with adequate personal assistance is added, then the number of people who may not be receiving community-based publicly supported attendant services who could benefit from such services could be estimated at 2,975,618 (3 million).

TABLE 8

COMPARISON OF HOME CARE SURVEY ESTIMATES OF NEED FOR ASSISTANCE WITH PERSONAL MAINTENANCE TASKS WITH NUMBER ACTUALLY BEING SERVED IN PUBLICLY FUNDED PROGRAMS FROM WID SURVEY

Age Group	1984 Total U.S. Population	Home Care Survey		WID Survey	
		% Needing Help With 1 or More Tasks	# Needing Help With 1 or More Tasks	% Being Served	# Being Served (FY84)
Children (17 & under)	62,688,000 (under 17)	.23%	144,182	.10% (under 18)	59,527
Adults (18-64)	145,430,000 (17-64)	.667%	970,018	.09% (18-60 or 65)	136,062
Aging (65+)	28,040,000 (65+)	6.67%	1,870,268	2.34% (60 or 65+)	654,798

The average cost per user of attendant services from the WID study amounts to $2,840 for all types of service. If this figure is multiplied by the estimated number of people not being served, 3 million, then the additional expense could be estimated to be approximately $8.5 billion.

SECTION III

CONCLUSIONS AND RECOMMENDATIONS

As this study clearly indicates, there is no comprehensive system of attendant services in the United States. There is no broad federal policy, rather, scattered references to personal assistance services are found embedded in policies established by Congress and federal agencies with respect to programs such as Medicaid and the Older Americans Act. Consequently, jurisdiction over federal personal assistance programs is divided among several different agencies. The programs that exist are funded by a wide variety of federal and non-federal sources. Responding to what they perceive as a major need, states have developed their own policies and programs, usually (but not always) making use of those disparate federal funding sources that are available. States have generally failed to benefit from the experience of other states, apparently because until recently there has been little if any communication between them. All this has resulted in personal assistance services which are fragmented, lack coordination, usually medically oriented, burdened with work disincentives, inequitably distributed across the United States, and delivered by personal assistants who are poorly paid.

The lack of a federal personal assistance policy has affected the lives of many of the 3.8 million Americans of all ages with disabilities who presently are either receiving personal assistance services which may be inadequate or who are receiving no publicly funded services at all. Many of these people are denied independent lives because they are forced to either 1) depend on relatives and other volunteers for personal assistance, 2) live in institutions because no community-based personal assistance services are available, or 3) make do with less than adequate services from a variety of providers over whose services they have little or no control.

The World Institute on Disability is committed to working with people throughout the country towards the establishment of a comprehensive, funded National personal assistance policy. We know how critical these services are to people with disabilities everywhere, and from our first hand experience in California, we have seen the benefits such services provide. The results of this survey have reinforced WID's awareness that the lack of a comprehensive national personal assistance policy consistent with the principles of independent living has contributed to the unnecessary isolation and dependency of untold numbers of North Americans with disabilities.

Given this situation, our foremost recommendation is that a federal personal assistance services policy consistent with the principles of independent living be established and that a national personal assistance program be developed. This program can be funded by the federal government and private insurers and implemented by the states in accordance with policies and regulations promulgated at the federal level. Just as it took the enactment of Medicare, Medicaid and the Older Americans Act to ensure that older people and poor people receive a more equitable share of this country's medical care and social services, it is now necessary to institute a National Personal Assistance Service Program in order to make personal assistance services available across the United States to all those who could benefit from them.

To this end **WID Recommends: 1) that meetings of federal and state policy makers with representatives of and advocates for people of all ages with all types of disabilities be convened and funded by the federal government. The purpose of these meetings would be to discuss the implications of this study and WID's recommendation in order to develop proposals regarding the development of a national personal assistance program for independent living; and 2) that the federal government study what other countries have done to incorporate personal assistance services into their national social service policy.**

We now present a series of other policy and action recommendations which should guide the development of a National Personal Assistance Services Program. The first thirteen of these were adopted by the National Attendant Care Symposium sponsored by the National Council on the Handicapped. The remaining four policy recommendations have been developed by WID as a result of its research. Following each policy recommendation is a series of recommendations for action in accordance with each suggested policy.

Recommendations

1. The program should serve people with all types of disabilities on the basis of functional need:

WID Recommendations: 1) that every state make personal assistance services available to people with disabilities of all kinds; 2) that more information be gathered on the availability, type of services offered and quality of separate personal assistance service programs for people with intellectual, mental and sensory disabilities; 3) that the extent of need for personal assistance services to these three populations be explored; and 4) that demonstration projects be funded that combine services to these three groups with services to people with physical disabilities and brain injury.

2. The Programs Should Serve People of All Ages:

WID Recommendations: 1) that every state make personal assistance services available to all age groups: 2) that projects be established to look at how children and adolescents who are disabled can benefit from attendant services; and 3) that states consider consolidating programs for different age groups.

3. The program should provide for the optimum degree of self-direction and self-reliance as individually appropriate and offer the users a range of employer/employee and contract agency relationships:

WID Recommendations: 1) that all programs allow users the choice of individual providers or trained home health aides and homemakers from public or private agencies; and 2) that a continuum for managing service delivery be made available, ranging from consumer management (to the maximum extent feasible) to total agency management; and 3) that users of short term periodic services also have the option to locate, screen, train, hire and pay attendants if desired; and 4) that policies be developed that presume consumers prefer self-direction and require an evidential finding that an individual does not want or is incapable of total self-direction.

4. The program should offer assistance with personal, cognitive, communicative, household and other related services:

WID Recommendations: 1) that all rural and urban areas in the U.S. have a program offering the full array of personal assistance services needed by disabled people of all ages and all disabilities - physical, intellectual, mental and sensory; 2) that the states which offer services through separate household assistance and personal maintenance/hygiene services programs establish new programs which combine these services in terms of service delivery as well as organizational structure.

5. The Program should provide services 24 hours a day, 7 days a week, as well as short-term (respite) and emergency assistance as needed:

WID Recommendations: 1) that all programs make services available 24 hours a day, 7 days a week; 2) that a pool of emergency assistants be maintained in every locality; 3) that respite services be established for all age groups in the 16 states that do not offer them and 4) that respite services be available on a long-term (2 - 4 weeks) as well as a short-term regular or periodic basis; and 5) that respite and emergency services be provided in the location the user requests, instead of being restricted to institutional settings.

6. Employment disincentives should be eliminated, and
7. The program should serve people at all income and resource levels on a cost sharing basis as appropriate:

WID Recommendations: 1) that Medicaid benefits or other federal health insurance be made available to disabled workers who are unable to obtain private health insurance at reasonable cost; and 2) that all personal assistance service programs establish an appropriate cost-sharing formula and a realistic income ceiling from which all reasonable disability-related expenditures are excluded.

8. Services should be available wherever they are needed (eg. at home, work, school, on recreational outings, or during travel):

WID Recommendations: 1) that personal assistance be made available to users, not only for personal maintenance, hygiene and mobility tasks and housework, but also for work, school and recreation needs as well; 2) that eligibility requirements not limit the geographic mobility of the individual, so that people needing personal assistance are allowed to travel outside a state and still retain coverage for personal assistance services; and 3) that employers in both the private and public sectors explore the possibility of making personal assistants available in the workplace as is already being done in Sweden (Ratzka, 1986).

9. Personal Assistants should receive reasonable remuneration and basic benefits:

WID Recommendations: 1) that attendants be paid at least 150% of the minimum wage with periodic increases to reflect inflation and growth in experience and qualifications; 2) that attendants receive paid sick leave, vacation and group health insurance benefits in addition to Social Security, worker's compensation and unemployment benefits; 3) that joint discussions between unions and users be instituted to explore ways in which users and assistants can work together to provide better benefits for each other.

10. .Training for administrators and staff of administering agencies and provider organizations should be provided.

WID Recommendations: 1) that the legislation establishing the program (as well as the implementing regulations) require that administrators and agency personnel undergo appropriate training; and 2) that qualified disabled persons who use personal assistance services play a significant role in this training nationwide.

11. The program should provide recruitment and training of personal assistants as appropriate.

WID Recommendations: 1) that all personal assistant training programs be imbued with the Independent Living philosophy; 2) that training programs be managed and administered by the Independent Living Centers, wherever possible; 3) that personal assistants be taught that, whenever possible, the bulk of their training will be provided by their clients; 4) that users of personal assistance be instructors in the training program; 5) that training of personal assistants not be mandatory in most cases; 6) that registration and special training be required for those working with people with mental or intellectual disabilities; and 7) that personal assistant referral, recruitment and screening services be available for users who desire them.

12. The program should provide effective outreach and training of consumers as appropriate.

WID Recommendations: 1) that all personal assistance service programs be required to undertake outreach efforts such as visits to rehabilitation centers, sheltered workshops and schools, as well as brochures, public service announcements on T.V. and radio, buses, and so on; and 2) that personal assistance service programs offer both training for consumers in management of personal assistants and follow-up.

13. Consumers should participate to a substantial degree in policy development and program administration.

WID Recommendations: 1) that every personal assistance service program actively recruit personal assistance users to fill administrative and management positions; and 2) that representatives of Independent Living Programs be included on policy boards and state/local commissions which establish personal assistance service policy, rules and regulations.

14. The program should not restrict individual providers from administering medications or injections or from carrying out catheter management.

WID Recommendations: 1) that programs allow personal assistance users to train independent providers in catheter management, injections and medication administration; and 2) that programs ensure that all providers are allowed to provide the full range of services, paramedical as well as non-medical.

15. Family members should be eligible to be employed as individual providers.

WID Recommendation: 1) that all family members be eligible to be paid providers at a user's request; and 2) that a cash "personal assistance allowance" be provided which the disabled

person can use to hire family members or to purchase services from the outside.

16. No one should enter a nursing home or institution unless a finding has been made that they cannot live at home even with personal assistance.

WID Recommendation: that all states institute mandatory programs to screen prospective nursing home admissions.

17. Mechanisms for accountability should be developed that take into account the user's need for independence.

WID Recommendation: that a conference of independent living activists, users and program administrators be convened to discuss the issue of liability more fully.

Conclusion

Personal assistance, particularly attendant services, is crucial to maintaining adults of all ages who are disabled in the community. Recognizing this fact, two key conferences were convened in 1985 by the World Rehabilitation Fund and the National Council on the Handicapped in conjunction with the World Institute on Disability to discuss the state of personal assistance services in the U.S. and Europe. The participants at these conferences - including representatives of the Independent Living Movement, state and national disability organizations, state and federal government, researchers, consumers and advocates - all concluded, along with WID, that a national personal assistance program for independent living must be established.

Maintaining the current non-policy will no longer work. What has emerged on a de facto basis as an outgrowth of existing federal programs is a medical model of personal assistance service delivery which is unnecessarily costly and inadequate. There is an ever growing population of older people needing attendant services and an increasing number of families unable to provide those services.

The situation, in short, is reaching crisis proportions. In order to deal with it, it behooves policy makers to give serious consideration to this study and the recommendations it contains.

THE WORLD INSTITUTE ON DISABILITY (WID) is a private, non-profit 501(c)(3) corporation focusing on major policy issues from the perspective of the disabled community. It was founded in 1983 by persons who have been deeply committed to the Independent Living Movement. Its mission is to promote the health, independence, well-being and productivity of all persons with disabilities. It is funded by foundation grants, technical assistance contracts and individual donations.

WID is a research and information center focusing on five policy and program areas which have significant impact on people with disabilities:

- ***Attendant Services:*** WID is studying the availability of attendant services around the country and has proposed policy recommendations in this area. It operates a national resource center providing information and technical assistance.

- ***International Development of Independent Living:*** It has been said that Independent Living is "the hottest new American export today." WID is actively involved in promoting international relations among disabled communities and has hosted visitors from twenty-five countries.

- ***Public Education:*** WID believes that the general public, disabled people and professionals in the fields of health care, aging, education, housing, job development and transportation need accurate information on disability and independent living. WID is also engaged in consultation and education with synagogues and churches on issues of architectural and attitudinal accessibility for elderly and disabled persons who wish to participate fully in the life of their religious communities.

- ***Aging and Disability:*** WID has identified the interface between aging and disability as one of its priority areas. It is engaged in ongoing work to build linkages between the disabled and elderly communities. In 1985, WID co-sponsored a major national conference titled, "Toward a Unified Agenda: Disability and Aging."

- ***Immunization and Injury Prevention:*** The polio virus has once again become a threat to people throughout the world. WID is determined to help eliminate the spread of polio by working with the United Nations and other organizations to make universal immunization a reality. In addition, WID is committed to the prevention of all disabling injuries, diseases and conditions.

Other attendant service publications which can be ordered from the World Institute on Disability, 1720 Oregon Street #4, Berkeley, California 94703:

- *Descriptive Analysis of the In-Home Supportive Services Program in California* ($10). Describes one of the most innovative programs in the country. Examines the history of the 25-year-old program, how it operates, who it serves, and its problems.

- *Swedish Attendant Care Programs for the Disabled and Elderly: Descriptions, Analysis and Research Issues from a Consumer Perspective* by Adolf Ratzka, Ph.D., published by the World Rehabilitation Fund, 1985 ($3). A consumer-based analysis of the attendant services system in Sweden by an economist who is a user of personal assistants.

- "Report on National Attendant Care Symposium" 1985 ($3). Proceedings from a national meeting sponsored by the National Council of the Handicapped. Includes recommendations for a national policy for attendant services along with recommended changes in existing legislation.

- "Attendant Services, Paramedical Services, and Liability Issues" (Free). Explores the issue of liability of providers of different skill levels performing personal service tasks. Gives consumer-based perspective along with data on how various states deal with the issue.

- "Summary of Federal Funding Sources for Attendant Care" by Hale Zukas (Free). Overview of the provisions for attendant services under Medicare, Medicaid, Social Service Block Grant, The Rehabilitation Act, and Title III of the Older American's Act

- "The Case for a National Attendant Care Program" by Hale Zukas (Free). An analysis of the federal funds presently utilized to finance attendant services, their inadequacy to fulfill the need, and the need for a national entitlement program.

- "Attendant Service Programs that Encourage Employment of Disabled People" (Free). Brief state by state description of programs encouraging employment, giving information on eligibility criteria, administrating agency, funding source, utilization and expenditures.

- "Ratings of Programs by Degree of Consumer Control" (Free). Ratings of each program's degree of consumer control based on the National Council on the Handicapped's ten-point criteria.

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Senator HARKIN. The subcommittee will stand adjourned.
[Whereupon, at 11:35 a.m., the joint hearing was adjourned.]

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